

**School of Design and Art  
Faculty of Humanities**

**Illustrating a case by using diagrams: Development of Social Inclusion of  
people with Down syndrome in Malaysia**

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## DECLARATION

To the best of my knowledge and belief, this thesis contains no material previously published by any other person except where due acknowledgement has been made. This thesis contains no material which has been accepted for the award of any other degree or diploma in any university.

Nurul Hanim Md. Romainoor

Signature : \_\_\_\_\_

Date : \_\_\_\_\_

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## **ABSTRACT**

This research is an interdisciplinary study that involves more than one branch of knowledge of study. This study has used Mixed Purposeful Sampling that collected data using Design Thinking model. With a sample size of 29 participants, the study attempted to link the multiple interests and needs of participants in the Malaysian care system. An empirical approach sampled qualitative research (data), and Soft System Methodology (SSM) was used to theorise the researcher's methods (Checkland&Poulter, 2010). The variables of Qualitative analysis data were synthesised through Design Thinking model and were analysed systematically using Soft System Methodology (SSM). The research study aimed at how can Design Research interpret and edit the raw data of a 'complex' case situation, such as Person with Down syndrome (PDS) rights and understanding barriers to social inclusion in Malaysia?

The gap in the knowledge briefly presented the concerns on PDS in public and private organisations that support PDS rights to life in Malaysia. The therapies and rehabilitation programmes in Malaysia have possibilities for overcoming exclusionary barriers of PDS to participation in society. Having programmes and activities in disability art education that promote a feeling of dignity and freedom is important. Two visual diagrams illustrate the Design Thinking model and SSM, which display two distinctly different models highlighting the differences in each research model. The limitation in adopting two different research models is the lack of adopting probability sampling techniques. This limitation may significantly limit a broader generalisation of the research result.

**Keywords:** Design Research, Systems Thinking, Visual Diagram, Down syndrome, Malaysia, Inclusive Education.

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## CHAPTER 1

### Background of Study

#### 1.1 BACKGROUND OF PROBLEM

This research is an interdisciplinary study it involves more than one branch of knowledge of study that involves social inclusion in education for people with disability. The significance of this study involves art education in therapies and rehabilitation programmes that provides possibilities for overcoming exclusionary barriers of PDS.

In this research study, firstly will look into how can Design Research interpret and edit the raw data of a ‘complex’ case situation such as Person with Down syndrome (PDS) rights and understanding barriers to social inclusion in Malaysia? The reason is that Design Research involves organising the concern regarding the efficiency of communication, the technology used, and the social responsibility at stake (Bennett, 2006).

In Design Thinking comprises a structured model that designers used to conduct a design research study. However, Lawson (1990) cites Cross’s (1982) earlier study that posited that scientific problem-solving was done by analysis while ‘designers’ solve problems through synthesis. Therefore, as there are gaps in Design thinking model that raise concern, which Thoring and Muller (2011) had argued, there are ‘numerous books and scientific publications about the topic of Design Thinking, but what is missing is a detailed and well-structured formal model of the actual method.’

The primary concern of Design Research is to develop a clearer paradigm and to have pragmatically more useful or better-justified strands. The biggest concern is how to structure existing concepts and theories, and avoid unnecessary abstraction at the same time. A framework is needed which defines and expresses what constitutes knowledge about that situation. It can also help draw a distinction between research and novel writings and make the research recoverable. The framework that can support Design Research, as well as interpret and edit the raw data in this study, is



Soft Systems Methodology (SSM). The processes in SSM are recoverable by anyone interested in subjecting the work to critical scrutiny.

Design research is a generalizable discipline, and it is important to develop a general theory of design (Friedman, 2003). Simon (1996) defines design as the process that devices a course of action aimed at changing an existing situation into the preferred ones. Looking into Vianna's et al. (2012) example that suggested that: 'by taking the trouble to conduct a systematic survey, the designer can pinpoint the causes and consequences of difficulties and be more assertive in seeking solutions.' As Vianna et al. (2012) claimed: 'Designers identify problems and generate solutions from them'.

Hence, how can Design Research interpret and edit the raw data of a 'complex' case situation such as Person with Down syndrome (PDS) rights and understanding barriers to social inclusion in Malaysia? Understanding the treatment towards PDS as historical document text provides information that eventually led to a new understanding. Below provide the characteristics of PDS and issue issues concerning disability in Malaysia as reflected in state and private efforts to improve social inclusion.

### **1.1.1 Understanding Trisomy 21 (or T21)**

The gaps between education and organisational services from the public and private organisation that support Person with Down syndrome (PDS) rights to life in Malaysia is the key subject of this interdisciplinary study. Down syndrome is known as a common disability occurring throughout the world. There are many strategies for the education of children with Down syndrome that are well documented in international literature (Bird & Thomas, 2002; Connolly, Morgan, & Russe, 1984; Dmitriev, 1982; McVay, Wilson, & Chiotti, 2003; Oelwein, 1995; Wisniewski, 1990). However, there is less research and understanding of educational strategies for the person with Down syndrome (or PDS) in the Malaysian context (Hoe, Boo, & Clyde, 1989).

People with Down syndrome have the inalienable right to improve their skill set. For many generations, society has been led to believe that having a child with Down syndrome is a burden (Lea, Williams, & Donahue, 2005; Pallister, 1982). Unfortunately, some sections of society continue to have a negative perception of people with Down syndrome and they face constant prejudgment. Additionally the advances in biotechnology research - such as MartaniT21 (Farrimond & Kelly, 2011) - have made it simple to identify the chromosome T21 in early pregnancy, thus providing the option to terminate.

Contemporary attitudes have not always been the dominant view. The early 14th-century painting titled 'The Adoration of the Christ Child' is the earliest known visual representation of Down syndrome, dated in 1515 (Bloemraad, 2011; Stevens, 1998). It is one of the first acknowledgements of a person with Down syndrome documented in history (See Figures in Chapter 2, Section 2.1). This documentation shows the welcoming of a child with Down syndrome in the community and could be considered a positive depiction. It was only later, in the early 17th century, that the scientific findings of Langdon Down's research presented the distinction of children having 'intellectual disability' as a syndrome (J. L. Down, 1866). The study described such children as 'cretins' were referring them as Mongoloids. Medical culture and social attitudes have shaped Langdon Down's research (J. L. H. Down, 1828-1896) and influenced the linking of minor physical findings to a particular disability condition. However, in the early 1960s an ethical issue was raised with the use of the word 'Mongoloid'. It was dropped from scientific use at the beginning of the 1960s in Asian genetic research and replaced with 'Down's' Syndrome (Clark, 1929; Gibson, 1978; Henry & Wagner, 1962). In the 1970s, an American revision of scientific terms changed it to 'Down' syndrome, but in the UK and other countries the term 'Down's' is still used.

### **1.1.2 Characteristics of Down syndrome**

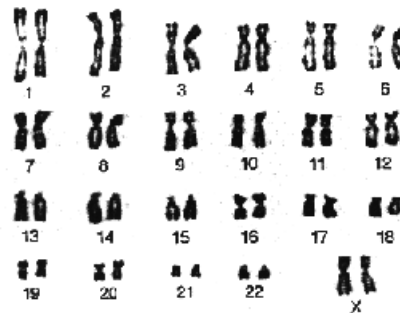
Understanding that many people who have an extra T21 chromosome can experience very sensitive emotions is necessary. Often the public underestimates the ability of such individuals. There was much speculation as to the origin of Down's syndrome. Waardenbur (1932) and Bleyer's (1934) in Frederick Hecht's study

(1994) was the first to suggest the syndrome was due to chromosomal abnormalities. In 1959, Jerome Lejeune and Patricia Jacob's work determined the cause to be a triplication of the 21st chromosome (Hecht, 1994). The cases of Down syndrome are due to translocation and 'mosaicism'. For example, Chromosomes are threadlike structures composed of DNA and proteins (Antonarakis, 1985). It stated to be present in every cell of the body and carries the genetic information needed for a cell to develop (Batshow, 2002). Studies on human cells normally have 46 chromosomes arranged in 23 pairs. In the 23rd pair are the sex chromosomes X and Y that carry the same information to the same genes can same spots on the chromosome. The differences of the gene are called alleles. For example, the genetic information for an eye colour is a gene, the variation of blue, green or grey are the alleles (Fukui & Ushiki, 2008).

According to science, Trisomy 21 is a genetic disorder caused by a chromosome abnormality (Wisniewski, 1990). Scientific studies have shown that human cells divide into two ways. First, there is the ordinary cell division is known as mitosis. In this process, the body grows to the extent that one cell becomes two cells that have the same number and the type of chromosomes as the parent cell. Second, there is the cell division that occurs in the ovaries and testicles meiosis and consists of one cell splitting into two causing the cell to have half the number of chromosomes of the parent cell. The regular eggs and sperm cells only have 23 chromosomes instead of 46. The results of a blood test research called karyotype shown in Figure 1 below (Batshow, 2002) categorised as a standard set of chromosomes. 22 are an evenly paired chromosome plus the sex chromosomes. The 'XX' means that this individual is a female.

Figure 1: 'Sample of a Karyotype'

Karyotype 1 (Batshow, 2002)

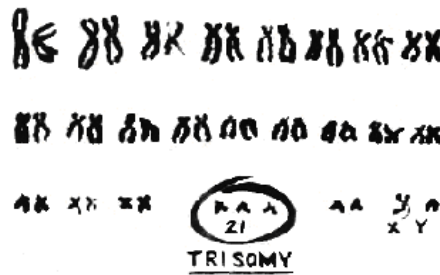


In the process of meiosis, the pairs of chromosomes split and move to different spots, dividing the cell in a process called 'disjunction'. However, occasionally a couple does not divide, and the whole pair proceeds to one place. The resulting cell will have 24 chromosomes, and other will have 22 chromosomes labelled 'non-disjunction'.

When a sperm or egg with an 'abnormal' amount of chromosomes merges with normal chromosomes, the result will fertilise an abnormal number of chromosomes. 95% cases of cases of Down syndrome caused by three sets of 21 chromosomes, known by the scientific name of 'Trisomy 21'. In recent research has shown that in these cases, approximately 90% of the abnormal cells are the eggs. The causes of 'non-disjunction' are unknown; however, it has been linked with maternal age (Batshow, 2002). Figure 2 below is a sample of 'karyotype' of a male with Trisomy 21.

Figure 2: Karyotype of a Male with Trisomy 21

Karyotype 2 (Batshow,2002)



This case is called ‘Down Syndrome Critical Region’ (Blank, et al., 2011; Bornstein, et al., 2010). The most popular theory suggests that only a small portion of the 21st chromosome can cause triplication to get the effects seen in Down’s syndrome. Having the presence of an extra set of chromosomes leads to overexpression of the involved genes and is demonstrated by specific cognitive, behavioural and physiological characteristics (Kuhn, 2010).

New opportunities, new challenges and new successes in understanding the background of Down syndrome are significant in building the quality of life for people with Down syndrome. New knowledge is constantly being charted inside an operating system that may become a complicated structure. Nobody can function alone; people with Down syndrome and his or her families interact together with professionals in the community that supports disability. Concerned individuals and the community as a whole interacting productively together is the ultimate goal that can bring the person with Down syndrome to have full potential in the community.

### **1.1.3 Intellectual disability rights in Malaysia**

The issues concerning disability in Malaysia as reflected in state and private efforts to improve social inclusion. The Person with Down syndrome (PDS) rights and understanding barriers to social inclusion in Malaysia are largely reviewed in the terms of OKU in Malaysia. The OKU (Orang KurangUpaya) or PWD (Person with Disability) in Malaysia has many concerns that have interrelating subjects regarding culture, religion, gender, and status. These matters are still more complex as they

also involve medical, social, economic, educational and political concerns. OKU, including persons with Down syndrome as people with an intellectual disability, face barriers to education and to obtaining a better quality of life. The challenge to OKU rights in Malaysia continues to be debated, even though 'inclusion' education has been recognised by countries as the US, UK, Australia and Canada for 50 years.

Disability policy in Malaysia is fundamentally a set of instructions for the inclusion of PWD in Malaysia (Ibrahim, 2009). It recognises PWD as possessing distinctive long-term, physical, mental, intellectual and sensory abilities and supports their privilege to own a respective OKU citizenship card. That provides them privileges for verification if they wish to obtain assistance from the 'state' and 'voluntary' organisations (Ibrahim, 2009). The disability policy influences 'state' authorities and 'voluntary' organisations attempts to support PWD. Jayasooria et al. study (1997) characterised this support in three ways. One is to encourage the wider community to take responsibility for PWD. Two, develop an ideology based on charity and good will that provides relief, including assistance to PWD and their family; and three, develop institutional mentorship in the provision of residential care, educational and vocational training. However, services were segregated from the institutional mainstream the massive boom in support services due to the disability policy act in 2008 as PWD are beginning to be managed by multiple stakeholders. With a little integration of services, Singh (2008), reports that coherent support for existing service centres is difficult to sustain.

One challenge to achieving OKU rights is the consolidation of different kinds of special education into one service organisation (Jayasooria, Krishnan, & Ooi, 1997; Saad, 2008). The 2008 Disability Act Malaysia raised advocates' concerns. The report stated the need '[t]o foster all levels of the education system. Including children from an early age, to have an attitude of respect for the rights of a person with disability' (Law of Malaysia, 2008, p. 14). Advocates argued that inclusive education in Malaysia faces implementation issues and persons with disabilities at all levels face exclusion from school. Special education programmes (Saad, 2008) in Malaysia are implementing programmes for children with visual impairment, hearing impairment and/or learning difficulties (Millennium Development Goals 2, 2004, p.

11). Some programmes are designed specifically for children with visual and hearing impairment, but there are no programmes catering to other types of people with disability including Down syndrome. It creates an environment of lopsided support and contradicts the report from the Cabinet in 1979. A review by Abdullah (2008) had stated, '[g]overnment should handle the education of all types of 'physically challenged' children. Government should take over solely the responsibility of the education of the organisations that operate at this time.' (Abdullah, 2008, p. 3).

There are public support organisations such as CBR (Community Base Rehabilitation) that are contributing their time and effort to accommodate persons with physical and intellectual disability. The support provides a child care centre for working parents and education and therapy sessions for people with disabilities. The CBR supports people aged five to nineteen years. The tasks for CBR support require a various array of support to manage the system. Such as rehabilitation professionals, carer and parents working together as a team to provide fully inclusive programmes for persons with Down syndrome. A study by Adnan and Hafiz (AirilHaimi&IntanAzreena, 2001) revealed that there are challenges in Malaysia in having groups of people with different backgrounds working together.

Subjects of inclusivity for people with Down syndrome and concerns in getting the necessary literacy education in schools have become complex in Malaysia (Ali, Mustapha, &Jelas, 2006; Jelas & Ali, 2012). There is evidence that literature review will discuss materials that suggest individuals with Down syndrome can have independent skills. Much literature placed an emphasis on the important role and suggested that family members play in the development of PDS and the network of communities that can provide social participation.

Experts suggested that PDS can develop quality skills in inclusive education. For example reading and writing, can emancipate PDS to live a quality way of life (Dmitriev, 1982; Nadel& Rosenthal, 1995; Oelwein, 1995). The review of the literature revealed a range organisational services that deeply woven into the

systematic development of learning and educational organisations and supporting areas, such as social and health care services (Frances Owen, 2009; Senge, 1990).

## **1.2 STATEMENT OF PROBLEM**

The gap in the knowledge discussed in previously reviewed briefly presented how the concerns on PDS in public and private organisation support Person with Down syndrome (PDS) rights to life historically and in Malaysia. Advocates had argued that inclusive education in Malaysia faces implementation issues and people with disabilities at all levels face exclusion from school.

20 years past suggested by experts in medical treatment for PDS found education to be the best therapy. Education allows inclusion of the intellectually disabled, such as PDS, into social communities (Stratford, 1994). Although, education are known to be old discoveries, enrolling PDS or children with other significant disabilities in public schools is difficult, but it is critical that they attend school. Having a child in school gives parents the confidence that their child can get an education to prepare them to function in an integrated society; that is, to live, work and play in the real world. Inclusion studies (Brown, 1995; Buckley et al., 2007; Falvey, 1995; Udvari-Solner, 1995) explain the various options for providing education for persons with disability (PWD). Such as participation in society in the form of disability arts that disability arts education has the potential to succeed because of its value as a form of conceptual critique.

Example of education model for bridging the gap between therapies and rehabilitation programmes for Down syndrome include Psychomotor Learning (Aparicio & Balaña, 2003), sensory integrative therapy (Uyanik, et al., 2003) and more. These treatment methods should be applied to support each other according to the individual needs of a child with DS (Uyanik, et al., 2003). In Allan (2005) study identifies possibilities for overcoming exclusionary barriers to participation in society in the form of disability arts that disability arts education has the potential to succeed because of its value as a form of conceptual critique and point of difference in playfully and pragmatically arranged programmes.



Research on live-birth of people with Down syndrome in Malaysia has estimated that 1:959 births are babies born with Down syndrome (Hoe et al., 1989). With love and care these babies grow to have fun, and with the guidance they can live a sustainable life (Gothard& Stanley, 2011; Skotko, 2011c). Studies in the field of disability in Malaysia have only a relatively recent history of examining social inclusion and inclusive education (AirilHaimi&IntanAzreena, 2001). Among the estimated 29 million people in Malaysia (AirilHaimi&IntanAzreena, 2001) 359,203 of them are reported to have a degree of disability (Department of Social Welfare Malaysia, 2012).

These suggested matters in training rehabilitation professionals, information to support people with disability, providing training and motivational support for parents, and training for government agencies and NGOs in developing services (Singh, 2008). OKU in Malaysia are faced with barriers to education for achieving a better quality of life. The possible reason suggested Malaysia is a developing country with incomplete diagnostic and funding structures. According to Kuar and Metcalfe (1999), there is considerable socio-economic and socio-politic pressure on the government to provide increased support, rather than basic care for different types of groups. Social inclusion in the context of disability has many interconnected aspects including culture, religion, gender, and status. These issues often further involve real life social, political, economic and medical problems.

### **1.3 PURPOSE OF STUDY**

The researcher determined that the data collection be too complicated to explain using the usual narrative descriptions. This research, therefore, aims to present, through visual diagrams aimed at illustrating case problems the disability sector in Malaysia. Visual diagram as information that can provide potentially positive future outcomes (in terms of skill development and their right to education) for people with Down syndrome.

This study aims to illustrate the research case problem by adopting visual diagrams to reveal a collaborative, interdisciplinary network of systems thinking, to

facilitate inclusive education. The intent is to review a real life case study of social inclusion and translate it into diagram form. The discussion of a real life case study is to position theoretical design research into practical outcomes to reveal structural sets (Love, 2000). In turn can spark new perspectives on information related to research in Philosophy of design (Buchanan, 2006; Frascara, 1988).

The opportunities for persons with intellectual disability to improve their quality of life is currently restricted by the challenge presented in getting groups of people to work together (to achieve a society better suited to caring). The principal goal of this research is to help emancipate persons with Down syndrome by providing clear knowledge of support systems to their ‘carers’ in the public and/or private organisations. Malaysia is a pluralistic society with an estimated population of 29.2 million (Department of Statistics Malaysia, 2012). Estimates of the cost of care and support for individuals with Down syndrome vary depending on the factors included in the costing and on geographic location. Today, Malaysia has a democratic political system that comprises various political parties representing the three major races in the country (Lee, 1999). Seven years from now, Malaysia is to meet Vision 2020 that aims to achieve a status of an industrialised and developed country. This research study is to present a clearer understanding of the challenges faced by the disability sector in Malaysia within that national vision (Samad et al., 2004).

In demonstrating the complexity, an interrelated cultural, political and social challenge has influenced the development of the Malaysian disability policy. This research study will develop diagrams that illustrate explicitly in visual form as an introduction of relevant information to a public audience. Researchers such as (Dubberly, 2008; Horn, 1989; Tufte, 1990) have used visual models to describe complicated social and cultural issues. In his book *Beautiful Evidence*, Tufte (2006) a statistician and a lecturer at Yale University, suggests that science and art have a common element that generates empirical information. He explains that, when seeing turns into showing, empirical observations turn into explanations, and evidence into presentations. His work has identified effective methods for presenting information providing tools for assessing the credibility of proof presentations. The

principal researcher has adopted visual application of the principles of analytical thinking as it helps both insiders and outsiders assess the credibility of evidence of this research study (Tufte, 2006).

Another example such as in Horn (2006) a political scientist who taught at Harvard University, has also presented his work in visual form as Information Mapping. His work on information mapping reports that '[t]he creation of detailed visual representations of what we do not know can illuminate the debates that revolve around crucial issues. They can provide a context and a depth of understanding when the precautionary principle is being invoked. Mapping of information can suggest missing variables in typical use of the idea of 'sound science', which in its common usage only focuses on what is, known.' (Horn, 2006). Other research (Barton & Barton, 1987; Dubberly, 2011; Medley, 2009), demonstrates the use of the visual model frames social data with simplicity.

Opportunities for change in the support of people with Down syndrome in Malaysia are first and foremost in the provision of the appropriate educational programmes for people with Down syndrome. It is important to align learning and skills development with the cognitive and physical limitations of the syndrome. In the field of PDS support processes, there is limited knowledge of how society and stakeholders respond about inclusive education, including Malaysia's disability policy (Jelas & Ali, 2012). Examples according to Kiernan (1995) there is a growing realisation of the importance of employment for people with Down syndrome. There is also an increasing recognition that the process of obtaining a job requires identifying the vision and expectations of the individual with a disability and matching that view to the work and social requirement of the job. It includes the support of on-site training, technology in the workplace, job redesign and accommodation, and the involvement of co-workers and supervisors as both trainers and support resources. These are strategies that have been effectively utilised to assist persons with severe disabilities in realising their employment goal (Kiernan, 1995). As, these concerns were discussed with interviewees during the research study; building a broad context for the central focus of the project is acknowledged. This research is primarily about research in design, and how design research can

illustrate and elucidate/or clarify social policy rather than a piece of social research, although the two closely entwined.

As Tufte (1983) had stated, ‘Communication is most effective and efficient when it is multimodal’. The research provides data that examines disability issues in the context of Down syndrome and the complexity of coping with the conditions of uncertainty in education and welfare support in the current organisation in Malaysia. This research recognises that disability issues in the Malaysian are experiencing the complexity and that there is a desire to have a systematic process to understand it. To map out a visual information approach is useful to this research because it helps to present complex data and frames the surrounding issues surrounding the Disability Movement in Malaysia. A mapping information approach can improve communication between the different organisations. Recognising, and then articulating complex, interrelated challenges presented in a structured visual diagram can clarify issues and the structures for applying for stakeholders. In this way, the options for stakeholders then become truly multimodal.

This research makes a substantial contribution to the knowledge of PDS support studies, inclusive education studies and Malaysia’s disability policy. The philosophical framework guiding this research is ‘systems thinking’ (Flood, 1999; Senge, 1990). The researcher was able to separate out objective circumstances by using a systematic thinking frame. It includes the claims of the body and stakeholder involvement in of the social body. An understanding of social claims is significant allowed the researcher to interpret data and re-present it to the community and stakeholders in a visual diagram.

#### **1.4 PRIMARY RESEARCH QUESTIONS**

The primary question of this research study, largely will look into how can Design Research interpret and edit the raw data of a ‘complex’ case situation such as Person with Down syndrome (PDS) rights and understanding barriers to social inclusion in Malaysia?

This research will study the influence of systems thinking and diagrams on the presentation of information on social inclusion. The idea of such data had

presented challenges in designing in a collaborative and interdisciplinary environment (Love, 2000; McDonald, 2006). There are two research objectives of this study. Firstly, an analysis of a theoretical design model that explores the development of social inclusion of Persons with Down syndrome (PDS) in Malaysia. The second is a design model that contributed to data findings illustrating the narrow aspect of social inclusion for Malaysian people with Down syndrome. This study will further discuss the theoretical implications of its findings to the philosophy of design and the practical outcomes of using the selected conceptual model. This research had gathered material for data with the focus on the main objectives of the study, discussed below:

Objective one: An analysis of theoretical design models

- (a) To identify an approach that can best demonstrate the characteristics of systems designed to reduce exclusion in the education of people with Down syndrome.
- (b) To understand the existing design and system thinking approaches for improving skills for people with Down syndrome.

Objective two: Design a model that illustrates the limited social inclusion of people with Down syndrome in Malaysia.

- (a) Through the use of a diagram, identify existing Malaysian structures that align with the education and empowerment of people with Down syndrome.
- (b) Evaluate the consequences of design model decisions in explaining the complex situation of disability issues for people with Down syndrome in Malaysia.

The aim is to contribute to better understanding, increasing the visibility of, and assistance for, people with Down syndrome in the context of Malaysia. Creating an avenue for success for people with Down syndrome, that is by giving them a sense of purpose in life with greater expectations also gives dignity to individuals and is the overarching intent of the research (Gothard& Stanley, 2011).

## **1.5 DISSERTATION OUTLINE**

This section describes brief information on the four chapters following this introduction and overview (Chapter 1).

## **Chapter 2**

This chapter reviews the literature regarding the development of Down syndrome support. The first section examines the phenomenon of supporting people with Down syndrome and examining how and why people with Down syndrome have the right to expand their knowledge and skills. The second section reviews the barriers to research in Malaysian society that has grown from being traditionally organised into a modern urbanised society. The last section will discuss the analysis of theoretical design models appropriate to the research task and justify the interdisciplinary lens that explores the development of social inclusion of people with Down syndrome in Malaysia as the case study.

## **Chapter 3**

This chapter discusses the methods and the research tools used in conducting the research data collection. The researcher has used qualitative design-based research approach to collect information from key stakeholders in Malaysia, and the methodology consisted of both a theoretical and empirical study that remain very closely linked together. An empirical approach sampled for qualitative research (data), and Soft System Methodology (SSM) was used to theorise the researcher's methods (Checkland&Poulter, 2010).

This study used Mixed Purposeful Sampling that collect data using Design Thinking model. A sample size of 29 participants in the study was attempted to link the multiple interests and needs of participants in the Malaysian care system. The reason for purposeful random sampling is to manage a study's sample size and to offer the researcher a process of discovering information through non-systematic ways. That is decreasing the influence of the researcher in framing information (Onwuegbuzie and Leech, 2007). This study used a small sample group. As the research intention was to establish the credibility of ideas within the discourse about the system, and not to make quantitative judgements about them (See: Chapter 3, pp. 94).

Instrument used are semi-structured interviews and the study of documents. This research study conducted a sample size of 29 participants from the groups listed in Table 1, which gathered with a snowball technique. The types of participants

comprised in categorised Table 2 below. The questions for the interview covered a combination of open-ended questions listed in Table 3 in Chapter 3 (see: pp. 101)

**Table 1: Participant Setting**

<b>Malaysia</b>
<ul style="list-style-type: none"><li>• Taman SinarHarapan, Cheras (TSH)</li><li>• PemulihanDalamKomuniti, KL (PDK)</li><li>• PersatuanSindrom Down Malaysia, Ampang (PSDM)</li><li>• Kiwanis Down syndrome Foundation, Subang (KDSF)</li><li>• Cheshire Home, Gombak</li><li>• Independent Families</li></ul>

**Table 2: Participant Groups**

<b>Participant Groups</b>
<ul style="list-style-type: none"><li>• Teachers</li><li>• Carers</li><li>• Parents</li><li>• Social workers</li><li>• Service Providers</li><li>• Volunteers</li><li>• Medical Professionals</li></ul>

## **Chapter 4**

Drawing from the ‘voices’ of participants has brought forward the key internal relationships within disability support services in Malaysia and intermittently linked these to the broader external environment. This chapter contains two parts. Firstly, variables of data are synthesised through Design Thinking model. Secondly, data were analysed and each research perspective are then organised systematically using Soft System Methodology (SSM). This research analysis and synthesis reveals that participants acknowledge that parental and organisational networked support for a child with Down syndrome (DS) is critical for the child to go on to lead an independent life. Both visual diagrams illustrated with Design Thinking model and

SSM will display two distinctly different methods of diagrams because of differences research model.

## **Chapter 5**

The idea of the study is to determine a better understanding of how a complex support system works and visualised. The concern of limitation in adopting two different research models is not adopting probability sampling techniques. A sampling technique that gives all sample collected in its process gives all the participants in the population equal chances of being selected. This sampling technique may significantly limit the researcher ability to make a broader generalisation from the research result. In turn limits the study's ability to qualify itself as a grounded study.

### **1.6 Definitions**

<b>Terms</b>	<b>Definition</b>
Bahasa:	Language
Brachycephaly:	From a Latin root meaning "short" and "head"
CBR:	Community Based Rehabilitation
Cognitive	
Impairment:	A person has trouble remembering, learning new things, concentrating, or making decisions
Community	A process where community members come together to take
Development:	collective action
Community-Based:	Focused on or relating to a community
Community-Based	
Continuum:	The process of working collaboratively
	The space in the skull within the protective case occupied by
Cranial Vault Bones:	the brain
	The process of replacing long-stay in psychiatric hospitals
Deinstitutionalisation:	with less isolated community
	Operates as a whole, including communication and
Family Functioning:	manipulation of the environment for problem-solving
Feeble-Minded:	Unable to make intelligent decisions or judgements



	A believe that all schools should be moving toward moving
Full Inclusion:	students with disabilities into mainstream classroom settings
Grass Root:	The most basic level of an activity or organisation
High Functioning	To be cognitively "higher functioning" (with an IQ of
Disability:	greater than 70)
ID:	Intellectual Disability
	Students learn the importance of individual and group
In-And-Out Inclusion:	contributions in less inclusive settings
Infanticide:	Infant homicide
Institutionalisation:	Committing a particular individual or group to an institution
KDSF:	Kiwanis Down syndrome Foundation
Kuhnian-style:	The Structure of Scientific Revolutions
Low Functioning	To be cognitively "higher functioning" (with an IQ of lower
Disability:	than 70)
Mainstream School	The practice of educating students with special needs in
System:	regular classes
	Genetic disorder where the lower jaw outgrows the upper,
Mandibular Prognathism:	resulting in an extended chin
Maxilla:	The bones forming the upper jaw and palate of the mouth
	A condition in which a person's head is significantly smaller
Microcephaly:	than normal for their age
	A situation in the upper jaw, cheekbones and eye sockets
Mid-Facial Hypoplasia:	have not grown as the rest of the face
MOH:	Ministry of Health
Morbidity:	The rate of sickness
Musculoskeletal:	Concerning both the muscles and the bones
	Branch of medicine dealing with intellectual disability
Neuropsychiatric:	attributable to diseases of the nervous system
NGO:	Non- Government Organization
OKU:	Orang Kurang Upaya @ PWD
Oxtotitlan Cave:	Natural rock shelter
Palpebra Fissures:	The elliptic space between the two open lids of an eye

PDK:	Pemulihan Dalam Komuniti @ CBR
PDS:	Person with Down syndrome
PSDM:	Persatuan Sindrome Down Malaysia @ Down syndrome Association of Malaysia
	Students learn the importance of individual and group
Pull-Out Inclusion:	contributions in practical inclusive settings
PWD:	People with Disability
	Failure to attempt to include the students with special needs
Rejection Of Inclusion:	in an ongoing activity
SEN:	Special Education Needs
SSM:	Soft System Methodology
	Refers to a range of services designed to help citizen with disability citizens retain their independence in their local
Supported Living:	communities
Thick Mandible	Jawbone that forming the skull with the cranium
Traditional Residential:	Model formed the basis for residential treatment preparing
Continuum:	patients/clients for life in the community
TSH:	Taman Sinar Harapan @ Garden of Hope
Two-Teachers Inclusion:	Collaborative teaching

## **SUMMARY**

This research is an interdisciplinary study that involves more than one branch of knowledge of study. In this research study largely will look into how can Design Research interpret and edit the raw data of a ‘complex’ case situation; the situation such as Person with Down syndrome (PDS) rights and understanding barriers to social inclusion in Malaysia?

Chapter 2 will discuss the literature and investigates the potential for the skills development of people with Down syndrome (PDS) in a global context. In particular, it identifies factors of exclusion and inclusion of education about disability and PDS in everyday life activities and programmes in Malaysia, which Malaysia has a relatively recent history of ‘inclusive education’. This chapter also justified the interdisciplinary lens that explores the development of social inclusion of people with Down syndrome in Malaysia as the case study.

## **CHAPTER 2**

### **Literature Review**

#### **INTRODUCTION**

The Person with Down syndrome (PDS) rights and barriers to social inclusion in Malaysia largely reviewed in the terms of OKU in Malaysia. It has many concerns that have interrelating subjects regarding culture, religion, gender, and status. Adults and children with Down syndrome have become the subjected to exclusion from education and everyday life. It is important to understand that many people who have an extra T21 chromosome are capable of having sensitive emotions. This chapter provides the literature review for the present study and investigates the potential inclusion education activities and programmes for the skills development of people with Down syndrome (PDS). In particular, Malaysia has a relatively recent history of ‘inclusive education’.

In section 2.1 reviews the phenomenon of supporting PDS and examines their rights to expand their knowledge and skills. Some studies have suggested for many generations, society has been led to believe that having a child with Down syndrome can be a burden (Bickenbach, 2009; Lea, Williams, & Donahue, 2005; Pare, 1982). As an interrelated field of study that involves more than one branch of knowledge, this chapter aims to explain the gaps in knowledge between education and organisational service that support PDS.

Section 2.2 reviews current barriers in Malaysia, which has grown into a multifaceted modern urbanised society. Complex socio-political and cultural factors are claimed to be contributing to the lack of rights for those with intellectual disabilities, including PDS. The gaps in the knowledge discussed presents how the concerns on PDS in public and private organisation support Person with Down syndrome (PDS) rights to life in Malaysia. This section aims to review advocates concerns on inclusive education in Malaysia.

Section 2.3 discusses the theoretical design model and the interdisciplinary lens used for examining the development of social inclusion of PDS in Malaysia. The significance of this section aimed at: how can design research interpret the raw data in a complex case. Such as the twinned issue of PDS rights and understanding barriers to social inclusion in Malaysia without positioning itself in a contextual ambiguity of ‘practice’ and ‘theory’? Therefore, this section reviews the relationships and categorisations in a visual diagram because the visual diagram is especially useful both for conceptualising ideas and utilising as a memory device.

## **2.1 DOWN SYNDROME PHENOMENA**

This section examines the history relating to Down syndrome (DS) and issues involving the feeling of prejudice and fear, health, family, socialisation and learning disabilities. It is important to reflect upon the broader history of the treatment of PDS to better understand Down syndrome exclusion in Malaysia. Many studies have declared that DS births occur as regularly as one in every 600 to 700 live births. The occurrence can happen in any part of the world, regardless of race, culture, religion, climate and status (Dmitriev, 1982; Hoe, Boo, & Clyde, 1989; Stratford, 1989; H. Wright, 2009).

Evidence of treatment of PDS goes back more than 3000 years. This early history was recorded among communities of the Olmec people (Stratford, 1994). This was before Langdon Down’s discovery of Down syndrome in the 19th century published in 'Observation on an ethnic classification of idiots' (Down, 1866). The evidence of the treatment of PDS in history has both positive and negative interpretations.

### **2.2.1 Treatment towards PDS as documented in history**

It is important to understand the treatment towards PDS as documented in historical texts. They provide information that eventually led to new understandings in the modern day view of PDS. In Ancient Greek and Roman, there was a

discussion about the specific biological characteristics of a PDS. They referred to PDS as vulnerable (Keele, 1964; Rosen, Clark, & Kivitz, 1976). At that time, however, children believed to be unfit or unwanted were discarded in sewers or left to die (D. Wright, 2011). Children with intellectual disabilities were referred to as 'idiots'. The belief in the selective breeding of humans was developed during Plato's period (427-347 B.C.): '... the best of either sex should be united with the best as often ... the offspring of the inferior, they are better ... put away in some mysterious, unknown place, as they should' (D. Wright, 2011). Furthermore, Aristotle posited that '[a]s to the exposure and rearing of children, let there be a law that no deformed child shall live' (Kellett, 1992; T.W. Smith, 1999).

Past literature presents evidence regarding the practice of infanticide, which was eventually discouraged as Christian philosophers proposed finding to care for people with disabilities. St. Paul (5-67AD) advised society to become more caring: 'To comfort the disadvantaged, support the weak, and be patient toward all men' (Kellett, 1992; H. Wright, 2009). After the Rome empire, examples of the existence of a more caring approach to society in Western culture can be found, which paralleled the development of the concept of Loathsome Imperfection, which gave rise to the enduring idea of Children of a Caring God or 'Les enfants du Bon Dieu' (Turina, 2013).



**Figure 3 Classic Olmec Figurine** (Milton & Gonzalo, 1974)

Evidence of the treatment of an even earlier history of PDS can be found in anthropological artefacts, which indicated that PDS were worshipped as a supernatural beings by the Olmec culture in ancient Mexico (Stratford, 1994). Statues and figurines showing people with deformity were assumed to be representing PDS as shown, for example, in Figure 3. The figurines suggest a worshipful attitude towards PDS. Experts Milton and Gonzalo in their 1974 expedition theorised that the Olmec figurines circa 1500 B.C – 300 A.D convey the myth in Olmec culture of humans mating with the jaguar. This is further supported by the existence of a painting in an Oxtotitlan cave depicting women of an older age bearing hybrid

babies (Milton & Gonzalo, 1974). These babies were referred to as ‘were-jaguar’ or ‘jaguar-babies’ and depicted similarities to Trisomy 21. Many anthropological findings have suggested that the ‘were-jaguar’ was a respected symbol (Milton & Gonzalo, 1974). However Pueschel (1998) argued that the characteristic features of a person with Down syndrome are not present. The physical evidence of the figurine in question is considered uncertain, thus making for widely disputed argument in the anthropological world.

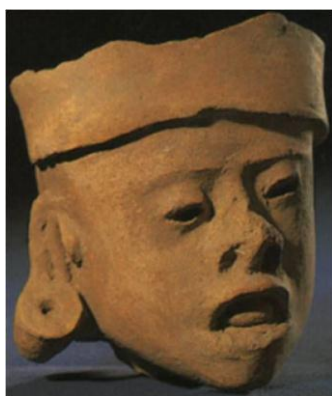


Figure 4: Terra-Cotta Figurine (Martinez-Frias, 2005)

In his book titled *In the beginning; new approaches to Down syndrome argued otherwise*, Stratford (1996) maintains that the ‘jaguar babies’ may have had Down syndrome and were perceived as a ‘God-human’ hybrid due to the following reasons. It was believed that the ‘jaguar babies’ were born to senior females of the tribe who had supposedly mated with a jaguar. His study suggests that because few ‘jaguar babies’ survived; this made them rare (Stratford, 1996).

Martinez-Frias’s study similarly shows that a ‘Toltec Figurine’ (Figure 4) from Mexico circa 500 AD appears to portray the physical features of Down syndrome. The report by Martinez-Frias (2005) highlights the discernible features of Down syndrome including short palpebral fissures, oblique eyes, mid-facial hypoplasia, an open mouth, and a protruding tongue. Stratford’s (1996) study on the ‘jaguar babies’ had identified figurines with similar features to that of the ‘Toltec Figurine’ discussed in Martinez-Frias’s (2005) study.

Other anthropological evidence includes a skull showing an individual with distinctive DS characteristics. It was first discovered by Brothwell in 1960 in a monastery at Breedon-on-the-Hill in North West Leicestershire in England. It has been dated estimated 700 to 900 AD and documented as

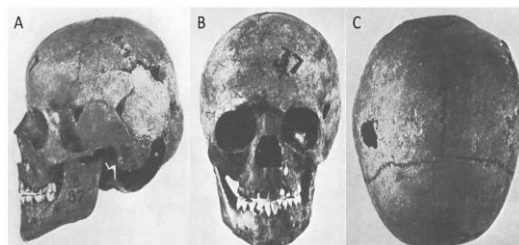


Figure 5: Skull of the Breedon-on-the-Hill (Brothwell, 1960)

having numerous features of a person with Down syndrome. Overall, the characteristics attributed by Brothwell (1960) to the skull (Figure 5) bear similarities to a person with Down syndrome.

Doll's (1967) text includes the tale of Martin Luther, who was known as the father of Reformed Christianity (1483-1546). The text examines the perception that people with intellectual disability harboured demons. These beliefs have persisted into the modern day and influenced the understanding of individuals with DS. Such beliefs also underpin how people with intellectual disabilities can continue to perceive as abnormal, remain segregated from the society, and subjected to cruelty due to physical and intellectual differences (Keele, 1964). However, this interpretation has changed significantly in more recent studies. As a case in point, Starbuck (2011) explains that Down syndrome is a unique biological feature and describes it as a significant neurodevelopmental disorder

### **2.2.2 PDS Exclusion in Education and Everyday Life**

In order to better understand the twinned issue of PDS exclusion and inclusion, it is relevant to continue examining historical examples and representations. Referring to Andrea Mantegna's painting, this is thought to have been completed in 1455AD, as an example, Levitas (2003) surmises that people who lived with significant disabilities such as PDS in Monastic communities received more positive treatment. Mantegna's paintings in Figures 8, 9 and 10 depict persons assumed to have Down syndrome during the Renaissance period (Levitas, 2003).

Starbuck (2011) reviews Mantegna's work as illustrated evidence of PDS from 1455AD, specifically *Virgin and Child with Saints Jerome and Louis of Toulouse* (Figure 6). The painting portrays the biological characteristic of a PDS. It represents a child with upwards slanting, small, widely spaced eyes, an open mouth with protruding tongue, short digits with an incurving fifth finger, and a weak nasal bridge with a buttoned nose. *Madonna and Child* (Figure 7) are estimated to be from 1460. The artwork also portrays characteristics of Down syndrome. The painting illustrates the child with epicanthic folds, small narrow eyes, an open mouth,



hypotonic expression, flattened nasal bridge and buttoned nose. The third painting *Virgin and Child* (Figure 8) is also estimated to have been done in 1460. Experts have debated whether the child in this third painting presents the characteristics of Down syndrome (Starbuck, 2011). They point out that Mantegna was a court painter, born to the rich and powerful Gonzaga family in Mantua, Italy. The debates are additionally related to whether the Mantegna or the Gonzaga family (or both) shared significant beliefs with regards to having a child with Down syndrome (Starbuck, 2011; Stratford, 1994).



Figure 6: Virgin and Child with Saints Jerome and Louis Toulouse (Andrea Mantegna (1431-1506))



Figure 7: Madonna and Child (Andrea Mantegna (1431-1506)) Painting first publish by Ruhrah (1935:477) Stratford (1982:252) Volpe (1986:431)



Figure 8: Virgin and Child (Andrea Mantegna (1431-1506))





Figure 9: The Adoration of the Christ Child [Night time] (Artist unknown, 1515 AD)(Kalkar, 1515)

There is other evidence of the positive treatment of the mentally ill in 16th-century Belgium, specifically in a community surrounding the Shrine of St. Dymphna at Gheel (Rosen et al., 1976). A famous example of an early image of Down syndrome is the Flemish (Belgian Dutch) painting *The Adoration of the*

*Christ Child* (Figure 9) by an unknown artist in 1515 (Levitas, 2003). It has

been argued that two of the represented individuals are thought to have Down syndrome and possess dissimilar facial features to those of the other characters in the painting. The first figure is an angel standing beside the Madonna. The angel displays a flatter face, up-slanting narrow eyes, epicanthic folds, flattened nasal bridge, upturned button nose, a downturned mouth, widely-spaced eyes and a hypotonic expression on the face.

The second figure is a shepherd boy located in the background in Figure 9. The figure depicts similar features to the first angel figure. For example, the biological characteristics include a distinct even face, up-slanting narrow eyes,

epicanthic folds, flat nasal bridge, a button nose, a downward turned mouth, widely-spaced eyes, and hypotonic expression. Experts distinguish that there is a second daytime version of the painting (Figure 10) where the characters are illustrated using a more typical look (Starbuck, 2011).



Figure 10: The Adoration of the Christ Child [Day time] (Artist unknown, 1515 AD) (Kalkar, 1515)

As cures for disability were unknown then, children born with disabilities were given care in monasteries, a practice referred to as oblation or offering. Examples such as the St. Mary of Bethlehem (1247) had evolved in most places in Europe in the 19th century. Issues concerning treatment for people with disabilities were considered by classical philosophers. A similar situation happens in the modern era with medical philosophers as in the Human Genome Project, for instance (Watson & Griffiths, 2009). The Project illustrates the potential for understanding the diverse nature of disabling conditions (Watson & Griffiths, 2009). It also highlights the potential for improved quality of life for many persons with disabilities. However, the possibility for termination of a foetus with a disability was also proposed. There are experts who consider that termination benefits the foetus by saving it from a life that would involve intolerable suffering (Pritchard, 2005).

By the beginning of the industrial era, perspectives were slowly changing. For example, the works of Edourd Seguin in 1846 focussed on the importance of educating people with disability. This expert stood up against negative attitudes. He took a genuine, professional and humane interest in the development of education for people with disability, including PDS, which in turn ultimately led to a change in the attitude of medical practitioners. As a pioneer advocate, physician and education specialist, Seguin developed pedagogy concerning the mentally ill. Published in 1846, *Traitement Moral, Hygine, et Education des Idiots* (or *The Moral Treatment, Hygiene, and Education of Idiots and Other Backward Children*) (Seguin, 1846) is widely regarded as the first textbook devoted entirely to the examination and treatment of the intellectually disabled.

This section will focus on the continuing exclusion of PDS in education and everyday life alongside continual advancements to counter or ameliorate exclusionary practices. Under discussion is the existing complexity of real world issues and everyday life for PDS. It will conclude with an explanation of the development of social inclusion of PDS in Malaysia.

## **Education becomes a treatment for PDS**

Experts in medical treatment for PDS have found education to be the best therapy because education allows inclusion of the intellectually disabled, such as PDS, into social communities (Stratford, 1994). Enrolling PDS or children with other significant disabilities in public schools is difficult, but it is critical that they attend school. Having a child in school gives parents the confidence that their child can get an education to prepare them to function in an integrated society; that is, to live, work and play in the real world. Inclusion studies (Brown, 1995; Buckley et al., 2007; Falvey, 1995; Udvari-Solner, 1995) explain the various options for providing education for persons with disability (PWD). These include therapies and rehabilitation programmes for Down syndrome. The programmes are planned to emancipate PDS living and learning in the community with training such as Psychomotor Learning (Aparicio & Balaña, 2003), sensory integrative therapy (Uyanik, et al., 2003) and more. These treatment methods should be a combination to support each other according to the individual needs of a child with DS (Uyanik, et al., 2003). Allan (2005) identifies possibilities for overcoming exclusionary barriers to participation in society in the form of disability arts. The study selected writers, poets and musicians. Allan (2005) concludes that disability arts education has the potential to succeed because of its value as a form of conceptual critique and point of difference in playfully and pragmatically arranged programmes.

There is an example of Psychomotor Learning in early intervention programmes that suggest that it can help PDS improve their fine-motor skills. Psychomotor Learning can support PDS increase their coordination of small muscle movements such as synchronisation of the hands and fingers with the eyes. A research was undertaken by Aparicio and Balaña (2003) to study an application of vicarious (second-hand) learning. The study was to determine whether subjects undergoing early motor training would benefit from the participation of parents in the early motor training of their children. The results obtained significant differences in the vicariously (second-hand) taught group compared to the parents taught through written instructions. The study suggests that parents of DS kids can play a vital role in educating their children.

Other studies suggest that the most crucial stage in growth development for the child with DS is the first 24 months. A visual diagram of the relationship between early guided programmes can demonstrate key strategies to increase the participation and communication to support the inclusion of PDS in Malaysia. It is important to develop psychomotor skills of an individual with DS in the first 24-month period. The particular motor activities to teach a child with DS include (1) gross-motor, (2) fine-motor, and (3) oral-motor.

In the first category, gross-motor activities include the use of large muscle control in the body. Dmitriev's (1982) *Time to Begin: Early Education for Children with Down syndrome* discusses the control over arms, legs and body. The activities in the gross-motor programme include head control, sitting, crawling, creeping and walking, which are all considered to be motor activities. A baby will first develop the movement for 'control of the head', and then the upper trunk and arms, and finally the legs. The gross-motor skills can occur in a developmental sequence in a 'cephalo-caudal' (general pattern of development) direction (Dmitriev, 1982).

The second category, fine-motor activities, includes the use of smaller muscles of the body. The activities in the fine-motor programme include coordinated hands and arms activities involving hand muscles, eye muscles, and hand-eye coordination. Fine-motor skills in the upper limbs occur in sequence. Oelwein's (1995) *Teaching Reading to Children with Down syndrome: A guide for Parents and Teachers* provides an example of how control of the shoulder and upper area close to the trunk simultaneously develops control of the fingers and hand.

Oral-motor activities involve activities that coordinate with the muscles around the mouth, tongue and jaw. Kumin (1994) found that many children with DS were experiencing motor delay and consequently reviewed oral-motor strength and coordination. Having delayed oral-motor control may lead to difficulties in feeding, drinking, talking and breath control. Activities in oral-motor skills often are related to feeding and drinking, which are considered pre-speech activities. Therefore, the recommended time to provide oral-motor activities is during mealtime because that is an important socialisation time (Kumin, 2006).

Brown (1995) maintains that the family's involvement in education and supporting their child with DS is important, but flags additional considerations. Some families have enough money to send their child away for private education, while others do not have the means to do so. Moreover, there are those who do not want to send their child away. There are situations where some families have no access to giving their children with DS even the most basic learning skills. This may cause parents to pressure the local government to build more institutions. There are also situations where families with a child or an adult with DS will invariably keep her or him at home.

Inclusion in regular education can be a challenging and difficult process of arranging instructions for children with a broad array of significant disabilities (Brown, 1995). Nevertheless, families who are experiencing such difficulty may wish to consider art education. Derby (2009) examines the issue of inclusion in art education. He suggests art education can work beyond a multidisciplinary education framework and is already moving towards a trans-disciplinary perspective on disability. Derby (2009) argues that studies in disability should play a more prominent role in multidisciplinary education. By connecting with pioneering trans-disciplinary expressions of traditional scholarship, theory and creative expression, and introducing performance, visual and literary art studies.

Every parent undoubtedly desires for their child with DS to be self-sustainable. To help achieve desires children must be equipped with an essential early learning education programme, which includes reading, writing, communication and numeracy at an early stage (Buckley et al., 2007). In most cases, the purpose of education programmes for children is to prepare individuals with DS to live, play and even work in an integrated society (Taylor, 1995). At the same time, however, many education programmes for individuals with significant disabilities such DS prepare them to work in a segregated society that consists of institutional awards, sheltered workshops, group homes or activity centres. In the case of inclusive education in public schools, many teachers face considerable professional pressure because they have not necessarily been trained to educate PDS (Taylor, 1995). Given these ever-present constraints, some activist studies suggest that graduates in art education

programmes can provide support in awareness about disability rights issues. Such case of disability rights, Blandly (1994) had suggested that art educators can collaborate with disability rights activists in promoting equality.

Due to their biological characteristics, PDS are known to have poor behavioural development and some teachers unfortunately simply identify them as 'naughty' instead of managing their behaviour (Bird & Thomas, 2002). In certain cases, a person who does not understand their rights is potentially more exposed to being abused. It is important to inform people about the nature of their rights, especially PDS (Owen & Griffiths, 2009). A person with Down syndrome is relatively manageable when placed in a mainstream setting. Inclusive education for many PDS is a reality both at primary and secondary level. Kieron Smith's (2011) study argues that PDS face difficulties communicating and can become a distraction for teachers and peers during a class interaction. Data evidence from Valentine Dmitriev (1982) and Patricia Oelwein (1995) suggests a successful inclusive method in educating PDS. Their studies on PDS education reiterate that it should start as early as infancy. The pioneering studies of Dmitriev and Oelwein in 1971 (cited in Royer, February 2011) previously established that PDS have high visual learning capabilities. They retain information better through visual activities than verbal activities. Dmitriev and Oelwein (cited in Royer, February 2011) suggest tailored material such as visual timetables and early focus on reading can provide PDS better access into the community.

At a young age, a child with DS can learn to read and talk simultaneously; the two skills interact and inform each other, as they do for every child (Oelwein, 1995). As Garton and Pratt (1989) point out, 'the development of written language skills influences spoken ability.' The new wording structures and functions happen by learning from writing, which is in turn adapted for talking (Garton & Pratt, 1989). Writing is to be encouraged as soon as a teacher begins teaching reading. Experts suggest tracing over words. The child with DS can learn to read by placing a traced word onto a flashcard. Then place in a book with plastic film on the pages, such as a photograph album (Dmitriev, 1982; Oelwein, 1995). This procedure helps to

develop a child's motor control and draws their attention to the letters in words from the outset (Garton & Pratt, 1989).

Another example is Picture Reading by using flashcards that involve discerning information from individual pictures. The sequences of images that occur in the community can become part of the Picture Reading instructions (e.g. on food labels) or sourced from emergency information posters (e.g. fire exit routes) (Oelwein, 1995). The first words chosen for flashcards are usually family names and words that the child comprehends and uses. The words should be printed neatly on flashcards, in lower case, and without any pictures because having pictures may distract the child's ability to capture the word as an image. Examples of insightful approaches to teaching reading outlined in *Ella Hutt's book Language through Reading* from 1982 (Hutt, 1986). The ability to read pictures also allows better clarity in the classroom, community, and on job-related tasks.

### **The Benefit of Environment for an Integrated Society**

Although the discussed issues dated in the mid-90s, it is still useful to understand the reasons for how it had influence Malaysia develop their inclusive education policy. Therefore, the past studies contributed to current decision making in Malaysia and the way inclusive education are perceived.

Studies have shown that the 'environment' is also essential in order to achieve a successful educational programme and enable satisfying integration for PDS (Wehman, 1995). Having an integrated environment such as an integrated classroom does matter in a successful inclusion programme for PDS. Kiernan (1995) posits that the more complicated, challenging and stimulating the environment, the higher the quality of life for PDS. Kiernan (1995) recommends that the best way to preparing



the child to function in a healthy, integrated society be to let them experience an integrated society by living, working and playing in the real world.

Additionally, Guay (1994) discerns there is a need for strengthening the scope in pre-service art education curricula to include teaching people with disabilities as the collaboration between special education and art education. The environment and effectiveness of art professionals can prepare them to interpret themselves through art making. However, to teach people with disabilities in integrated classes requires the art educator to be fully aware of special education curricula in non-art special education courses such as psychology or general education courses (Guay, 1994). An expanded scope is important because some art teachers with no instruction in the area of disability feel less than adequately prepared for teaching students with disabilities in integrated classes (Guay, 1994).

McLean's (2008) study involved people with a disability in a project titled 'The Story Project'. The project engaged with twelve adolescent participants with a variety of disabilities, including Down syndrome, autism, and Asperger's syndrome. The principal finding was to let the participants convey and interpret themselves through art-making. The researcher suggests that these participants can be successfully included in the classroom community when schools provide the appropriate tools such literacy in the arts.

In a study by Virji-Babul et al. (2003), the PDS participants had their total movement time tracked after each trial performance. The entire trial production project involved a game and the movement time informed as a "score" on each test.

Participants were also given verbal encouragement throughout the task. According to Virji-Babul et al. (2003), their participants with PDS had improved action skill over the presented trials in both movement performance and coordination of action sequences even under conditions when visual data is restricted.

At the same time, however, Heslam (2011) offers a cautionary note. Lifelong learning is required for PDS. Given that PDS receive an annual health check, Heslam (2011) posits that the clinician can play a bigger role in promoting the Health Care Guidelines for Individuals with Down syndrome for PDS Lifelong Learning. Additional issues ensue with the increase of health problems after school age. Schwab's (1995) study shows that while inclusion is becoming a current reality, proper medical treatment is not yet popular for adolescents and adults with DS. The study explores how the transition into adolescence is a stage whereby individuals experience dramatic physical and emotional change. Individuals typically experience sexual maturation, explore intimate relationships and seek to establish independence from their parents. Adolescence is a particularly important time for PDS because they would experience cognitive and other disabilities, factors that can significantly alter the natural progression. While the increase in the lifespan of PDS allows them to experience more of life's realities for longer periods of time, this longevity correspondingly also includes facing issues of poverty, unemployment, lack of relationships, frustration, social isolation, family conflict, and other negative life experiences (Schwab, 1995).

Another challenge posed by the greater longevity of PSD means the majority of parents will be outlived by their children. Some parents/caregivers claim to feel

dissatisfied with the service providers and believe they know more than the service providers (Meyers & Peuschel, 1991). These parents are faced with arranging additional support through a group home or other residential arrangement, and are likely to seek guardianship or trusteeship to look after their son or daughter after they have died. The lack of relatives caring for them and the small number of individuals with DS reaching adult age make it difficult to achieve effective clinical follow-up (Rasore-Quartino & Cominetti, 1995).

Assessing the clinical well-being of adults with DS is necessary. Their medical and neuropsychiatric examinations should occur every year as they can help improve rehabilitation or social integration (Lauras et al., 1995). Individualised planning is recommended as it is necessary to ensure a successful transition from childhood to adulthood. Medical experts recommend the needs of individuals with DS require involvement in partnership with families and community-based professionals (Schwab, 1995). Studies have shown it is important to have an accurate schedule of management for the child with DS, and it should start early with the cooperation between parents and professionals (Lauras et al., 1995).

The family unit is the primary natural environment for members of any society. Every child belongs to a family and family connections are of lifelong and primary importance in their life. Bradley (1995) argues that persons with intellectual disabilities or other developmental disabilities be also entitled to be part of a family. Even when parents are encouraged by medical and social service professionals to seek an institutional replacement for children born with severe disabilities (Bradley, 1995). There has been a considerable improvement in infants with intellectual

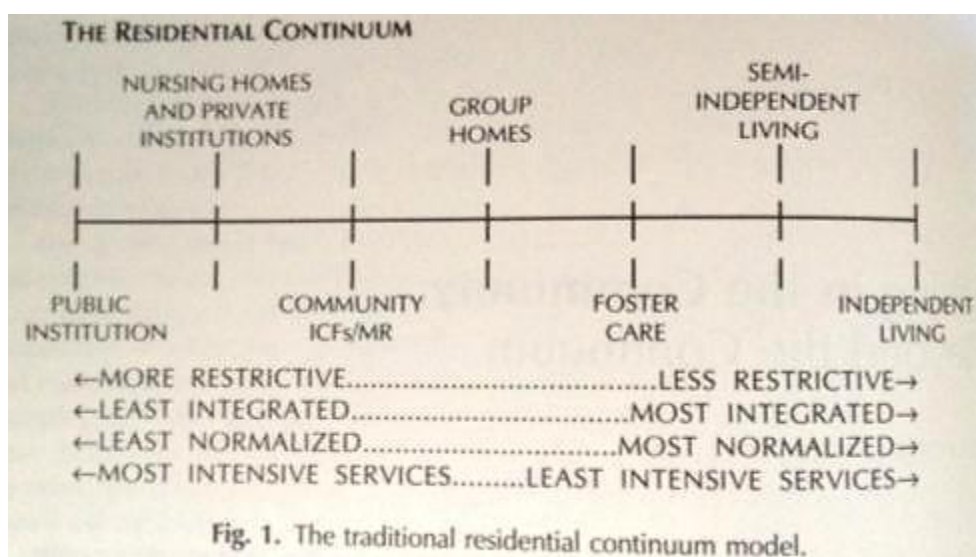
disability surviving past infancy when living at home with their families (Ashbaugh et. al, 1995). There are additional indications that the development of ‘family support policy’ has progressed in three phases. First is the era of institutionalisation, followed by the era of deinstitutionalisation and community development, followed in the end by the period of community membership (Bradley, 1995).

Community membership places an emphasis on ‘functional support’ to enhance community integration, quality of life, and individualisation. The focus is on the creation of a network of the formal and the informal that meets day-to-day demands in homes and communities (Bradley, 1995; Ferguson & Olson, 1989). The assumption of functional support is that the presence of a child with a disability affects the functioning of the entire family. Failure to nurture ‘family functioning’ invariably places the child at risk for out-of-home placement. The increased provision of services and facilities to support children with disabilities would place new demands on service providers (Ferguson & Olson, 1989; Levitz & Schwartz, 1995).

Approaches to supporting PDS and other developmental disabilities to live in the community are referred to as ‘supported living’ or ‘housing and supports’. The early conceptualisation of assisted living according to the Least Restrictive Environment (LRE) principles defines operational practice in terms of continuity. The ordered sequence of placements may change according to the degree of restrictiveness (Taylor, 1995). Standard ways that represent LRE are from the most restrictive to the least restrictive alternative, or a hierarchical cascade of placement options. The most restrictive placements are the most segregated and will offer the most intensive

services while the least restrictive placements are the most integrated, geared towards living independently and provide the least intensive services. In between there are nursing homes and private institutions, community intermediate care facilities for what remains known as the mentally ill, community residences or group homes, foster care, and semi-independent living or transitional apartments. Figure 11 displays the 'traditional residential continuum model' by Taylor (1995).

Figure 11: The traditional residential continuum model (Taylor, 1995)



The community plays a role in influencing PDS participation in everyday social activities. Research in behavioural technology documented by Taylor (1995) introduces the question of how to expand the range of involvement for people with intellectual disability. These include people with Down syndrome, severe intellectual disability, autism, severe cerebral palsy, and deaf-blindness. The challenge is to encourage the service providers that provide programmes in the community to critically re-examine and re-evaluate their practices. Taylor (1995) suggests that rather than spending money on support services to place persons with disability (or PWD) in segregated day programmes, this money should be reallocated

to supporting job coaches who work with individuals in the community (Wehman, 1995).

The principles of LRE have led from the ‘traditional residential continuum’ to the creation of a new ‘community-based rehabilitation’ (CBR) (Taylor, 1995). CBR designed as a guiding principle for people with developmental disabilities and their families. People with the most severe disabilities usually placed in more restrictive and less integrated environments. The CBR programme aims to eliminate segregated environments and includes settings that range from group living arrangements at the most restrictive end to independent living at the least restrictive end (see Figure 13). Specific residential programmes can be found in the CBR, including small, community-based intermediate care facilities for the intellectually disabled, community residents or group homes, three or four-person mini group homes, supervised apartments, apartment clusters, and semi-independent living situations (Halpern, Close & Nelson, 1986). The traditional continuum, however, assumes that people with severe disabilities will live in more restrictive institutional settings while persons with mild disabilities will live in less restrictive smaller settings (Crissey & Rosen, 1986).

Studies have shown that persons with DS who are living and learning well in the community have an increased lifespan. Examples documented in books, articles, and policies have communicated the positive value of living and learning in the least restrictive environment for people with developmental disabilities. However, challenges continue to exist in terms of helping people with developmental disabilities and supporting them in living successfully on their own in the community. Examples include arranging methods to help PWD to live and participate in community life (Chernets, 1995) and the provision of employment support for PWD.

## **The Maintenance of PDS Behaviour**

The environments are an important element in an inclusive education, to maintain PDS behaviour is also a necessary. The importance of understanding PDS behaviour from the discussion of old studies are significant because to employ PDS effectively into an inclusive education environment.

Today, the lifespan of an individual with DS has changed worldwide. In the early 1900s, individuals with DS had a lifespan of only up to 9 years of age. Studies reviewed in Brown's (1995) article show that the PDS lifespan increased to 50 years of age in the 1950s. The rise in lifespan for PDS may bring about other social challenges in the form of dating or marriage. In the 1990s, 1 in 10 was assumed to live to 70 years of age. PDS today are expected to live even longer. Studies have recommended that PDS should be prepared to live a normal lifestyle. Early childhood development intervention is a proven accomplishment (Burns & Gunn, 1992; Dmitriev, 1982; Miller, Leddy, & Leavitt, 1999; Stratford & Gunn, 1996). However, PDS are likely to continue to face prejudice.

As modern medicine advances, research has proven that persons with Down syndrome have a biologically distinct characteristic that influences their behaviour (Nadel, 1988). The behaviour of an individual with DS can easily stereotype as problematic (Manion, 1995). However, in many cases, the behavioural strengths of persons with DS include general sociability and acceptance of others, sensitivity and empathy, artistry and creativity, and a strong sense of family and community. These qualities are often overlooked (Manion, 1995). Manion (1995) has categorised the behavioural deficits and excesses in DS. These include self-help skills (e.g. eating, toileting), academic skills, language, social skills, appropriate play, motor skills, short-term memory, and auditory-motor processing, attention span, problem-solving and safety discrimination.

For example, *Behavioural deficits* are behaviours that are considered to be inappropriate due to their nature, frequency or the circumstances in which they occur. There have been examples where medical doctors have looked upon the

treatment of DS behaviour as ‘a hopeless waste of time and effort’ (Stratford, 1994). Stratford (1994) provides an example of a doctor’s communication to a parent: ‘Your baby is a Mongol, take your broken doll home’. For Stratford (1994), the comment is both disturbing to others and dangerous to the child/individual concerned. While, *Behavioural excesses* can be observed in children. Parents have variously reported it as attention seeking behaviour, habits and rituals, over-activity, destructiveness, wandering away, undifferentiated display of affection, non-compliance and general stubbornness (Manion, 1995). Emotional difficulties such as extensive worries, fears, and sleep difficulties are not uncommon in PDS and can be added to the general list of behavioural concerns. However, Manion (1995) finds it inappropriate to look at the problematic behaviour without considering the associated behavioural strengths. This includes the positive impact that individuals with DS often have on their environment and the people around them (Manion, 1995).

Children with DS are no longer expected to die young, a circumstance widely credited with improvements in health care and medicine. The development of antibiotics and a cleaner environment have meant that children with DS, who have reduced immune system function are less prone to infections. However, PDS are still at risk of developing movement or motor difficulties. 50% of all children with Down syndrome are born with heart defects (Nadel, 1988). PDS are typically associated with varying degrees of cognitive impairment (Haslam, 1995). Trauma to the head and neck may cause personality changes (Nadel, 1988). Functional abnormality can inhibit progress in learning. PDS often have significant musculoskeletal disorder, obesity and malnutrition; these are important factors about social development. Experts suggest the loss of skills can trigger emotions leading to apathy, social withdrawal, and daytime sleepiness, followed by loss of self-help skills (Pueschel, 1988). Functional abnormality limits the capacity of PDS to participate in sports and recreational activities, which are necessary for their physical and emotional development.

Difficulties in the area of motor development are common and can lead to behavioural excess and rejection as suggested by Manion (1995). Examples include certain behavioural problems such as running off or inadequate safety, discrimination



and problem-solving skills. In turn likely to cause parents to restrict outdoor play and limit play contacts and activities for their child (Byrne, et al., 1988). Lack of social events can also cause PDS behavioural abnormalities, which may influence the cognitive development and can lead to depression. It is critical to have better knowledge of early stimulation programmes in locating the potential of each child's ability (Hanson & Harris, 1986). Research indicates that early stimulation activities can lead to real benefits. The development of hearing, vision, cognitive, social and motor development is necessary for the newborn stage to reduce the risk of poor developmental function in their growth (Nadel & Rosenthal, 1995). It is the optimal strategy for promoting a better quality of life for PDS (Dmitriev, 1982; Hanson & Harris, 1986; Oelwein, 1995). The continuation of early stimulation activities with monitoring and follow-up programmes is required to support PDS to have the sustainable living.

Another circumstance is influencing PDS social development and their medical problems, for example, is obesity. Studies have indicated that PDS often have problems with obesity (Cronk, C. E., et al., 1985; Roizen, Luke, Sutton, & Schoeller, 1995). The kinds of available treatment for PDS to battle obesity include behaviour modification, diet and exercise (Roizen et al., 1995). Setting a daily exercise programme for PDS from an early age and doing it part of the daily routine is another useful strategy. For instance, regular exercise, daily walks and daily vitamins including mineral supplements can be tailored to suit individual needs (Roizen et al., 1995). Progress in clinical care and early rehabilitation can lead to a standard life for children with DS. They can attend normal schools, participate in sports, and enjoy their lives much like their peers (Chumlea & Cronk, 1981). It is nonetheless important throughout the transition from infancy to adulthood to maintain regular clinical follow-ups. The gaps of knowledge between education and organisational service that support PDS important to reflect upon the broader history of the treatment of PDS to better understand Down syndrome exclusion in Malaysia may lack to understand that PDS has biological.

## **2.2 FACTORS INFLUENCING THE DEVELOPMENT OF SOCIAL INCLUSION IN MALAYSIA**

This section reviews the major issues concerning disability in Malaysia as reflected in state and private efforts to improve social inclusion. Studies in the South East Asian community have emphasised that '[u]nderstanding the psychosocial impact of an inherited condition in affected individuals and their family requires an understanding of the cultural context in which they are situated' (Bryant, Ahmeda, Ahmed, Jafri, & Raashid, 2011).

Malaysia is a tropical country, traditionally covered with lowland rain forests (Tarling, 1962). The climate is equatorial and characterised by the annual south-west and northeast monsoons (Bastin & Winks, 1979). Malaysia is the 43rd most populated nation in the world with an estimated population of 29 million in 2012. Kuala Lumpur is the official capital city and the largest city in Malaysia, whereas Putrajaya is the federal administrative capital. Kuala Lumpur is recognised as the legislative capital of Malaysia and the main commercial and financial centre of the country (Kuar & Metcalfe, 1999). All government policies are based on the concept of the New Economic Policy (NEP). It is a form of affirmative action with preferential treatment for indigenous Malays in education and business (Lin-Sheng, 2003; Mohammad, 1970).

In the late 20th century, Malaysia's economy advanced towards industrialisation (Drabble, 1999). What influenced its urbanisation were economic growth between the 1980s and the mid-1990s (Ang, 2009). In the mid-1990s, there was a cultural shift from an agriculture-based economy to a manufacturing and industrial-based economy in areas such as computers and consumer electronics (Ang, 2009). The physical landscape of Malaysia changed with the emergence of numerous mega-projects (Ang, 2009, pp. 148; Kind & Ismail, 2001). The booming economy in Malaysia resulted in the increased performance in terms of life expectancy, education and health measures. Essentially Malaysia aims to attain developed nation status by 2020 (Jayasooria, 1999, p. 350; Snodgrass, 2004, p. 14). Malaysia's urban population had increased to an estimated 70% of the total

population in 2008 while the rate of urbanisation had risen by 3% of the annual rate from 2005 to 2010 (Department of Statistics Malaysia, 2010). Malaysia is a newly industrialised country, which means there are now more opportunities for people with disabilities (PWD) to be part of social life (Jayasooria, Krishnan, & Ooi, 1997, p. 456).

### **2.2.1 Demographic**

Malaysia is a multi-religious nation with complex ethnic and cultural structures (Arles, 2003, p. 527). The three main ethnic groups are Malays (50.4%), Chinese (23.7%) and Indians (7.1%) (Arles, 2003, p. 527). Islam is the religion of the Federation and the Malays while the majority of Chinese adhere to Buddhism, Confucianism or Taoism (Arles, 2003, p. 527). According to a census report in 2000, 60.4% of the population is Muslim, 19.2% Buddhist, 9.1% Christian, 6.3% Hindu, and 2.6% Traditional Chinese Religion including Confucianism and Taoism, with 1% other or unknown and 0.8% no religion (Central Intelligence Agency, August 3, 2010).

The primary language spoken in Malaysia is Bahasa Malaysia. It is also known as the official language even though English, Chinese (Cantonese, Mandarin, Hokkien, Hakka, Hainan, Foochoow), Tamil, Telugu, Malayalam, Panjabi and Thai are widely used as well (Arles, 2003, p. 527). The smaller communities consist of social groups that speak different dialects (Arles, 2003; Central Intelligence Agency, August 3, 2010). In East Malaysia, many other languages are widely spoken including indigenous languages such as Iban and Kadazan (Central Intelligence Agency, August 3, 2010).

### **2.2.2 Disability Policy History**

Orang Kurang Upaya (OKU) is the term used in Malaysia to refer to PWD. Social inclusion in the context of disability has many interconnected aspects including culture, religion, gender, and status. These issues often further involve real life social, political, economic and medical problems. OKU in Malaysia is faced with barriers to education for achieving a better quality of life. More importantly,

PDS are categorised as intellectually disabled and there are still many challenges for OKU rights in Malaysia even though disability care has been recognised for the past 50 years (Jayasooria & Ooi, 1994).

The concept of disability in Malaysia has been considerably influenced by the definition provided by the World Health Organisation (WHO) and International Classification of Functioning, Disability and Health (ICIDH). The concept of disability in Malaysia is framed within the medical model of disability with a principal focus on impairments, not limits modelled by the social environment (Sinnasamy & Kuno, 2006). In May 2001, the ICIDH changed its name to the International Classification of Functioning (ICF) and brought about an improved conceptualisation of disability support worldwide and in Malaysia. However, Disability Act into Law of Malaysia (2008) recorded that Malaysia has not responded sufficiently in terms of social policy. The increase of social and health policy in Malaysia concurrently followed the growth of the global trend in framing health within the context of 'well-being' and 'self-management'. Thus, social health care is evolving towards a broader focus on sharing and understanding (Dubberly, Mehta, Evenson, & Pangaro, 2010; Jayasooria et al., 1997).

Social work with physically challenged persons in Malaysia originated in the first attempts of the Anglicans in caring for the blind during the 1920s. In the following decade in the 1930s, the state was granted responsibility for the care and treatment of leprosy patients (Sinnasamy & Kuno, 2006). State intervention in social services in 1946 saw the establishment of the Department of Social Welfare (Baginda, 1992; Jayasooria & Ooi, 1994; Kinzie, Sushama, & Lee, 1972). Services for the care of physically challenged people expanded. Sinnasamy and Kuno (2006) suggest that the services and responsibility for people with disabilities developed during three periods: (1) institutional care (1940 -1960); (2) emergence of self-help organisations (1960 -1980); and (3) Community-Based Rehabilitation (CBR) in early 1980s. As reported in Sinnasamy and Kuno's (2006) study, the scope of aid for people with disabilities was implemented by both public (government) and private (non-government) service providers. An overview of the historical development of the Department of Social Welfare in Malaysia is provided in the following Figure 12.

Figure 12: Historical Development of the Department of

Social Welfare in Malaysia (Sinnasamy & Kuno, 2006)

Year	Name of Department/Ministry
1912	Migrant Welfare Program (colonial administration) – abolished in 1930s
1937	Social Service Department (under the Colonial Office)
1946	Department of Social Welfare
1952	Department of Labour (Introduction of Almoners or Medical Social Workers by Ministry of Health)
1956	Ministry of Health and Social Welfare
1958	Ministry of Labour and Welfare
1960	Ministry of Health and Social Welfare
1963	Ministry of Labour and Social Welfare
1964	Ministry of Welfare Services
1982	Ministry of Social Welfare
1990	Department of Social Welfare (Ministry of National Unity and Social Development)
2004	Department of Social Welfare (Ministry of Women, Family and Community Development)

Malaysia faced criticism that argued a caring society need to contribute more improvements to the well-being of people with disabilities (Human Rights Watch, 2010). The concept of care must be replaced with the notion of equality and human rights (Jelas & Ali, 2012). Since then, there have been significant measures to improve the situation of people with disabilities. In Figure 13, Sinnasamy and Kuno (2006) present an overview of the historical milestones in disability support in Malaysia. Historically, there have been responses that addressed issues of social exclusion in different ways. However, they have largely alternated between welfare and charity, rather than the provision of opportunities that allow participation in all institutions of society including employment (Marcus, 2009; Wong, 2010).

The Malaysian disability legislation established in 2008 is still relatively new; nonetheless it specifically lists the protection of the rights and well-being of PWD. An analysis of the brief history of disability support in Malaysia shows the steps taken to help people with disability in the country. Malaysia has been a signatory to the UN Declaration of the Rights of the Disabled Person since 1975. It was followed by participation in the Convention on the Rights of the Child in 1989, Ratification on the Proclamation on the Full Participation and Equality of People with Disabilities in Asia and Pacific Region in 1994 and the most recent adoption of the BIWAKO

Millennium Framework for Action with UNESCAP in 2002. Additional legislative steps have been taken to ensure an inclusive, barrier-free and rights-based society for persons with disabilities in Asia and the Pacific region between 2003 and 2012.

Figure 13: Important Milestones in Disability in Malaysia (Sinnasamy & Kuno, 2006)

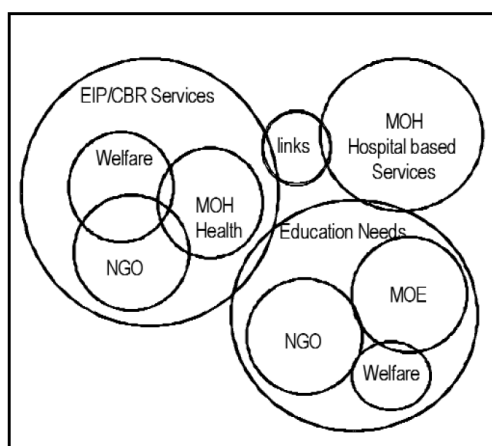
YEAR	MILESTONES
1981	International Year of Disabled Persons
1981	Inter-ministerial Responsibilities on the Welfare of Disabled Persons
1982	World Program of Action Concerning Disabled People
1983 – 92	UN Decade for Disabled Persons
1990	National Implementation Committee for the Well-being of the Disabled
1990	National Welfare Policy
1991	Incorporation of guidelines for barrier-free access into the Uniform Building By Laws
1993 – 02	Asia Pacific Decade for Disabled Persons
1993	Standard Rules on the Equalization of Opportunities for people with Disabilities
1994	Ratification of the Proclamation on the Full Participation and Equality of People with Disabilities in the Asian and Pacific Region
1994	National Advisory and Consultative Council for people with Disabilities
1995	Opening of the Bangi Rehabilitation Centre
1995	Established the Special Education Department
1989	Memorandum to the National Economic Consultative Council 1
1999	Campaign for the Asia Pacific Decade for the Disabled
2000	National Census included Disability
2000	Memorandum “Beyond 2000 ~ Equal Opportunities and Rights for People with Disabilities” to the National Economic Consultative Council 11
2001	UN General Assembly Resolution on a Comprehensive and Integral International Convention to Promote and Protect the Rights and Dignity of Disabled People
2002	Memorandum “Employment of Malaysians with Disabilities: Removing the Barriers” submitted to the Minister of Human Resources
2002	BIWAKO Millennium Framework for Action
2003 – 12	Extension of Asia Pacific Decade for Disabled Persons
2003	Public Discussions and Feedback on the Proposed Draft Legislation “Malaysians with Disabilities Act”
2003	Series of Forum hosted by the National Human Rights Commission (Suhakam) on Disability Issues

Despite these significant developments, the general perception of disability in Malaysian society is problematic and people with disabilities continue to be subjected to discrimination either directly or indirectly (Sinnasamy & Kuno, 2006). It has been pointed out that Malaysia’s greatest tendency is to rely on political pronouncements. This is perhaps the main directive that is required rather than appealing to the public conscience and goodwill in addressing issues concerning the needs of a physically challenged person (Jayasooria, 1999).

### 2.2.3 Disability support in Malaysia

The appropriate infrastructural support is also required to help develop disability rights. At present within a service organisation, there may be different facilities using divergent methods (Jayasooria et al., 1997; Saad, 2008). The study by Adnan and Hafiz (2001), reports that a significant factor in helping to overcome current challenges is to coordinate how groups of professionals work together. This includes providing training for professionals, training and motivational support for parents, and training for government agencies and NGOs on developing services (Singh, 2008). Singh's (2008) study reports there is currently little integration within the field and that combining new efforts and the existing service is difficult to sustain. As displayed in Figure 14, current support involves the interests of different organisations such as Hospital services in Ministry of Health (MOH), Education services in Ministry of Education (MOE) and Community-Based Rehabilitation (CBR) services in Department of Welfare (Singh, 2008).

Figure 14: Overview of Current Malaysia Disability Services (Singh, 2008)



The support that involves the interests of a different organisation could also potentially create a bias. Abdullah (2008) states, 'With this awareness, the government should handle education of all types of physically challenged children. Government should take over solely the responsibility of the education of the organisations that operate at this time.' For example, special education programmes in Malaysia include the implementation of programmes for children in public schools (Saad, 2008). These programmes involve children with visual impairment, hearing

impairment and learning difficulties (Millenium Development Goals 2, 2004). However, students with intellectual disabilities such as Down syndrome, Autism, developmental delays, Attention Deficit Hyperactivity Disorder (ADHD), and other learning disparities are usually placed in self-contained classes (Jelas & Ali, 2012).

According to Kuar and Metcalfe (1999), there is greater socio-economic and socio-political pressure on the government to provide increased disability support for the different groups. The debates concerning creating opportunities for persons with disability in Malaysia are thus caught between taking steps to improve their quality of life and getting groups of professionals to work together to provide better care (Singh, 2008). Social inclusion in Malaysia is currently restricted by the challenges presented. Following Sinnasamy and Kuno (2006), this list summarises the major issues and concerns:

- **Education Article 23 of the Convention on the Rights of the Child (CRC)** states that a disabled child has the right to special care, education and training to help him or her to enjoy a full and decent life in dignity and achieve the greatest degree of self-reliance and inclusion possible.
- **Vocational training and employment:** the need to increase training facilities to teach skills that are relevant to prepare disabled people in the public sector and the reluctance to provide employment despite the incentives available in the private sector.
- **Accessibility and transportation:** the lack of enforcement of the uniform building by Laws that ensures that all new public buildings are accessible is a gross violation of human rights while appropriate toilet facilities, parking lots, accessible roads and disabled-friendly public transportation are critical issues.
- **Disability statistics:** the current figures available from the DSW do not provide accurate information on the actual numbers of disabled person in Malaysia making it very difficult to budget and provide adequate resources.
- **Financial and equipment support:** current financial assistance is insufficient to cover costs of living today and requests having been made for additional assistance for the disabled poor and the unemployed, and personnel and adequate financial allocation for non-government organisation (NGO).



- **Political representation:** disabled persons are increasingly vocal and want to participate in the political process. Campaigns to register voters during elections ignore their right to information and inaccessible voting booths prevent them from electing candidates of their choice.
- **Community based rehabilitation:** it is generally acknowledged that CBR is an alternative or complementary approach to rehabilitation in institutions and that it has brought about positive changes in the lives of disabled people. It has particular strengths in the prevention and detection of disabilities. There are concerns that CBR is currently too medically oriented and must change to reflect the human rights approach and be modelled according to the Independent Living (IL) concept.

#### **2.2.4 ‘State’ and ‘voluntary’ support**

The disability movement in Malaysia was in effect initiated after the Second World War when the then colonial rule provided institutional relief for PWD who had suffered from chronic illness, blindness and loss of limbs (Arokiasamy, 1987). The period from the 1940s to 1960s is known as Malaysia’s significant period of growth for ‘structural change’, which saw both state (public) and voluntary (private) provisions for a disabled person increase. Arokiasamy’s (1987) study *The History of Rehabilitation Services in West Malaysia from 1957 to 1982* chronicles the shift from voluntary support to the development of social work in 1946 with the setting up of the first Department of Social Welfare. Its function was to care for the physically impaired, blind and intellectually impaired. The establishment of Jubilee Home in 1953 was among its earliest projects. The Home included a residential centre supporting the intellectual and physically impaired and children with disabilities.

The Central Welfare Council (a state initiative) was also established in 1953 to foster the voluntary efforts of local welfare and charitable organisations that were encouraged by the Malaysian Government. That was due to the fact it was evident that all needs could not be adequately met and sustained solely through statutory involvement (Jayasooria et al., 1997). Accordingly, the wider community was also encouraged to take responsibility and help provide relief and assistance to charities while institutional support provided residential care, educational and vocational

training. Due to the institutional character of services at that time, PWD were segregated from the mainstream society (Jayasooria & Ooi, 1994).

The issue of care support is continually evolving in the face of the critical evaluation. The disability movement is not grounded in traditional forms of political participation through the party system or from within single-issue pressure groups targeting political decision makers (Jayasooria and Ooi 1994). The disability movement is seen as culturally innovative in that it is part of an underlying struggle for genuinely participatory democracy, social equality and justice which has risen out of an industrial culture.

Consequently, efforts in CBR in Malaysia have been viewed as strategies to achieve programmes dealing with PWD and their families at a community level (Ramakrishnan, 2007). CBR was first introduced in 1983 in Kuala Terengganu by means of state effort under the sultanate. Due to the increased popularity of the WHO, CBR was soon expanded into every district in Malaysia after 1995 (Ramakrishnan, 2007, p. 10). The methods for support PWD were, at that time, shared between the state and voluntary organisations. However, there were some undesirable trends; some PWD organisations were perceived as being elitist because of organisational structures and personality differences. Consequently, the participation of grassroots PWD organisations are now limited (Jayasooria et al., 1997).

The social and community context of inclusion has changed in Malaysia as a result of reflecting an emerging priority to support the 'developmental' aspects of social welfare. There is the need to build a capacity for anticipating social problems and family involvement and community participation (Baginda, 1992). The social and community development framework is one of the fundamental aims of the National Social Welfare Policy; the idea is to strengthen and improve the family unit and community (Kandiah, 1992). However, the Malaysian social work techniques were mainly an adaptation largely shaped by Anglo-American influence. The method of risk intervention is essentially individual-focused (Harper, 1991) as reflected in the introduction in Jones's book on *Social Welfare in Malaya*:

During the period of British administration in Malaya, the Social Welfare Services were based to a considerable extent on patterns evolved and found successful in the United Kingdom. This was both inevitable and advantageous, because there was no distinctively Asian social theory, so that it was necessary to adopt the pattern of the West; and advantageous, since the West has adopted those patterns after more than a century of trial and error, and Malaya was saved many years of experiment in the early stages (Jones, 1958).

These perspectives described by Jones (1958) are deeply rooted in the ‘internationalist view’ in which there are might well be different modes of social work but fundamentally they are all the same (Payne, 2005). The viewpoint of an ‘international opinion’ was deemed satisfactory then. Nevertheless, differences in local cultural perspectives subsequently warranted the expansion of methodologies and conceptual structures to reflect different viewpoints on social work. For example, an ‘Eastern’ model of social work highlights the social interdependence of families and the community’s greater acceptance of responsibility for direct practice in comparison to the policies of self-determination premised on Western ideologies of individualism (Midgley & Chow, 2004; Payne, 2005).

The question of the significance and appropriateness of Western theories and methods has also been considered within Malaysia (Kinzie et al., 1972). The identities of modern-day citizens in a changing Malaysian society show intercultural adaptation and transformation through education (Arokiasamy, 1987; Yahya, 1994). As Fulcher and Faizah (2000) suggest, the definition of social work in Malaysia should therefore be shaped by the consideration of how culture influences both ‘help-giving’ and ‘help-receiving’ among people in this particular context without relying too much on Western social work theory (Fulcher & Faizah, 2000).

### **2.2.5 EXCLUSION AND INCLUSION FACTORS IN MALAYSIA**

The process of accepting inclusion in the context of the Malaysian education system is discussed in this section. In the first world, many countries have achieved acceptance in terms of the social inclusion of people with disabilities, including Down syndrome, in the last two decades. Such acceptance includes social,

mainstream school and occupational frameworks (Rogers, 1993, May). Heiman (2004) explains that the term ‘inclusion’ is an action of including or being included in a group. In terms of inclusion in Education, there are four different models: (a) in-and-out, (b) two-teachers, (c) full inclusion, and (d) rejection of inclusion. Heiman (2004) discovered that most teachers in the United Kingdom and Israel thought an in-and-out inclusion model would be more beneficial for students with learning disabilities. Other research from Smelter (1994) also disagrees with the full inclusion of PWD due to the different learning styles of children with disabilities.

Education is necessary for the development of persons with disabilities. Historically, persons with a disability were regarded as inferior and dependent (Lawson, 2007; Place, 2010; Wilton, 2006, p. 130). People with disabilities remain largely outside the education system and labour market (Lawson, 2007, p. 9). Due to the growing number of support services, PWD is beginning to be managed by multiple departments. However, with little integration, as previously discussed with reference to Singh’s (2008) report, the endeavour to combine new efforts and existing service centres is difficult to sustain. In Figure 14, Singh (2008) shows how current forms of support involve the interests of different organisations.

The policy for a barrier-free standard in America was the key that kick-started the disability rights movement in the early 1960s (Salend & Duhaney, 2011). It set up a modern trend that has driven the aim of reducing PWD exclusion into a worldwide phenomenon (Keele, 1964). The attempt to translate such foreign policies into the Malaysia context was incorporated into the Education Act 1996. Jelas and Ali (2012) offer a history of how Malaysia embarked on a three-stage development process towards inclusive education. The first stage was the opening of the first school for the blind in 1929 and later on the first school for the deaf in 1954. The schools were initiated by the Ministry of Social Welfare which is known today as the Department of Social Welfare under the management of the Ministry of Women, Family and Community Development. The second stage occurred when professionals prepared programmes for special education, formally established by the Minister of Education (MOE) in 1961. The third phase came about when Malaysia started importing knowledge and expertise by sending their professionals abroad for

research into ‘special educational needs’ in the 1980s and 1990s. Malaysia soon participated in international workshops and activities organised by the United Nations (UN) and United Nations Educational, Scientific and Cultural Organisation (UNESCO). These new initiatives resulted in amendments to the Education Act 1996 in Malaysia and the development of changes to policy (Jelas & Ali, 2012).

Malaysia’s Disability Act 2008 is discussed by Ibrahim (2009) who suggests that the Act became a set of instructions for inclusion of PWD in Malaysia. The Act required that ‘those with a long-term, physical, mental, intellectual or sensory disability ... possess a respective OKU citizenship card for verification, if they wish to obtain assistance from the state and voluntary organisations’ (Ibrahim, 2009). The Act helps to characterise the roles of state authorities and voluntary organisations in three ways. Firstly, it encourages the wider community to take responsibility for PWD. Secondly, it attempts to motivate by mutual understanding and an ideology based on charity and goodwill that provides relief and assistance to PWD and families. Thirdly, institutional care takes the form of residential care, as well as educational and vocational training, however, institutional services, are segregated from the mainstream society (Jayasooria et al., 1997).

Ramakrishnan (2007) suggests that the disability issue in Malaysia may drastically change due to innovations in science and technology. Such innovation enhances urbanised lifestyles. However it may not radically redefine the term ‘disability’ because it cannot automatically bring about changes in the lifestyles of PWD (Ramakrishnan, 2007; Sharizad, 2010). Research nonetheless suggests that one way to reduce exclusion is through the creation of job opportunities or placements (Abdullah & Mey, 2011) and building a sustainable environment (Jayasooria et al., 1997). However, some research has also reported there are employers unwilling to employ PWD because of concerns regarding safety regulations.

The focus on rights of education in the context of the lives of people identified with intellectual disabilities has not been prevalent in much of the research literature in Malaysia despite the development of local programmes (Adnan & Hafiz,

2001; Jelas & Ali, 2012). There is limited information on Down syndrome support in available in Malaysian scholarly journals. Research, therefore, has to refer to evidence from other societies as examples to help frame and understand the issue of Down syndrome exclusion in Malaysia. The importance of looking at the history of inclusion worldwide is to grasp an overall decision made globally which in terms influences Malaysia factors to exclusion and inclusion policy making.

## **Intellectual Disability in the Disadvantaged Society**

As Malaysia has conducted a statistical review of PWD registered with the social welfare department, and PDS categorised under 'intellectual disability' data. The estimated total of PWD registered with Malaysia's Department of Social Welfare (DSW) is shown in Figure 15. The DSW – or Jabatan Kebajikan Malaysia (JKM) in Bahasa Malaysia – reported that 359,203 people in total were registered in 2011 (Department of Social Welfare Malaysia, 2012). The population of PWD in 1997 was 69,753 so the estimated total had increased by 289,450 (Abdullah & Mey, 2011; Salleh, 2008). In 2012, the total population of Malaysia was estimated to be 29,348,520 million (Department of Statistics Malaysia, 2012) and the actual number of PWD is estimated to be 5% to 10% of the total population. This estimate suggests that the approximate number of PWD in Malaysia is between 1.43 – 2.85 million and counts as one of the most disadvantaged communities in Malaysian society. Hoe (1989) analysed the statistics for live births including the number of newborns with DS in 1989. Out of the 34,522 live births in Kuala Lumpur's maternity hospital, 36 of them had Down syndrome. By extrapolation, it is estimated that Malaysia has a ratio of 1:959 or 1 baby with Down syndrome to every 959 live births (Hoe et al., 1989). This is comparable to other parts of the world. The median estimate of live birth with Down syndrome in North America is 1:700 live births (Martinez-Frias, 2005). From 1964 to 1970 in West Jerusalem, the estimated overall rate of Down syndrome was 1:833 live births (Harlap, 1973). In Japan, there are 5.82 DS births per 10,000 live births or 1:1030 according to the estimated ascertainment ratio (Hoshi et al., 1999). The rate of DS live births varies slightly worldwide, and Down syndrome remains a global concern.

Figure 15: Registration of PWD categoried by type of disability

(Department of Social Welfare Malaysia, 2012)

<b>Type of Disability</b>	<b>Year (2011)</b>
Blind	31,924
Hearing	43,788
Physical	123,346
Learning Problems	134,659
Speech Problem	725
Intellectual Disability	8,927
Other	15,834
<b>Total</b>	<b>359,203</b>

Adults and children with Down syndrome continue to be subjected to exclusion from education and everyday life in Malaysia. Studies by Jelas and Ali (2012) and Haimi & Azreena (2001) argue that there be problems transferring inclusion policy into practice. The uneven adoption of disability rights in multiple public and private agencies in Malaysia was resulting in a discriminatory and unsystematically planned method of inclusion. In the case of individuals with DS, protecting their rights through networks of support and teaching community understanding with regards to their behavioural characteristics are of utmost importance. The community needs to learn that PDS have significant biological behaviours, and PDS in turn need to understand interaction with the public better. PDS are sometimes shy, can be over-affectionate, and sometimes overly aggressive (Buckley, 1995). There is an urgent need for methods to address the complexity of inclusion rights within the context of Malaysian society. The future move towards connecting parents, carers, and professionals in a learning organisation will provide meaningful support for PDS.

Various policies and programmes have been introduced to improve the quality of life of PWD since the International Year of Disabled Person in 1981 (Ramakrishnan, 2007). Lee (2006) posits that disability issues challenge the regulation of nationalism, cosmopolitanism, citizenship, and multiculturalism. These questions are also closely connected to the concept of identity, group representation,

minority rights, civil society, and civic engagement (Lee, 2006). There are various methods for achieving better equality for person with disabilities, according to Rioux and Valentine (2006), but at core these require the engagement of all political, administrative and judicial stakeholders in understanding the meaning and experience of disability. Hence, as McColl (2006) suggests, those in relevant positions of authority need to provide planning information for policy makers, and furnish statistics for advocacy disability groups. Disability issues in Malaysia continue to be viewed as a complex, 'ill-structured problem' which are the concern of various people having very different perceptions in a problem, as suggested in experts studies (Horn, 1989; Mitroff, Mason, & Barabba, 1983)

In the Malaysian PWD context, a child must be 'educable' to be eligible for placement in a mainstream school. This reflects a narrow interpretation of the concept of inclusion (Jelas & Ali, 2012). However, Malaysia's efforts in inclusive education are gradually translating policy into practice. The term 'pupils with special needs' and 'special education programmes' were introduced in the Education Act 1996 (Abdullah, 2008). It categorised students with 'special needs' as students with visual impairment or hearing impairment or learning disabilities (Jamaluddin, 2011). Jelas and Ali (2012) stated that the current special education programme is a three part process. Firstly, the training programme provides special schools for pupils with visual impairment or hearing impairment. Secondly, the teaching programme provides an integrated programme in general schools for students with visual or hearing impairment or learning disabilities. Thirdly, the training programme in inclusive education curricula for pupils with special needs enables those who qualify the opportunity to attend mainstream classes together with mainstream pupils.

Individual health professionals, medical practitioners, and officers from Ministry of Education (MOE) and the Welfare Department of the Ministry of Women, Family, and Community Development (MWFCDD) have the authority to determine the methods of how PWD students are valued by the community. The Education Act 1996 assumed that there are students who are unable to obtain an education in the public school system. CBR settings have consequently become the



principal educational organiser for the student's learning development (Jamaluddin, 2011; Saad, 2008). CBR programmes are state-initiated and centre-based programmes at the community level. They aim to provide education, treatment, and rehabilitation training for children with learning disabilities (Kuno, 2000).

According to Adnan and Hafiz (2001), having a disability does not mean that a child is automatically eligible for educational provision. Application processes and procedures are still required with respect to the criteria for children classified as having learning and intellectual disabilities. Moreover, the examination by various medical experts is required to validate claims of high-functioning or low-functioning disability (Jelas & Ali, 2012). A key contradiction arises when current policies appear to enforce a state standard for the eligibility of PWD students (Jelas & Ali, 2012). Jelas and Ali (2012) argue that the state standard for the eligibility of PWD contradicts the goals of providing equal educational opportunities as stated in the UN's Standard Rules in the equalisation of opportunities for PWD in 1993, the Salamanca Statement 1994 and the BIWAKO Millennium Framework for Action 2002.

Hence, PWD who are identified with an intellectual disability such as Down syndrome, mild autism, developmental delay, attention deficit Hyperactivity Disorder (ADHD) or specific learning disabilities are placed in self-contained, special classes under the management of the Department of Social Welfare (Hashim, 2008). The struggle for equal rights and access to support is still evolving in Malaysia as policymakers and schools put into practice their interpretation of what they perceive those rights to be (Jelas & Ali, 2012).

## **Transferring Disability Policy into Education**

A level of balance has been achieved in terms of unity in cultural diversity in Malaysia on the basis of the division of responsibilities and functions among the major social and ethnic groups (Arles, 2003, p. 527). The social change provides possibilities for altering the view of disability development in the future

(Ramakrishnan, 2007, p. 11). The Malaysian government plans to become an industrialised nation by the year 2020 (Jayasooria, 1999). However, the economic success of the country, attained through industrialisation, would have little meaning if there is no development of a caring society especially in respect to traditional values of caring (Mohammad, 1990). The number of PWD expressing their concerns has increased, paralleling the emergence of rapid social urbanisation in Malaysia. PWD in Malaysia have nonetheless seen better involvement in issues concerning their welfare and future since the Malaysian Confederation of the Disabled (MCD) in 1985 as reviewed in the study by Jayasooria et al. (1997).

There are new challenges in building a vibrant and modern nation. These include transferring policies and practices of disability inclusion and intellectual disability rights into a community and educational organisations (Jelas & Ali, 2012). Inclusion in education is becoming popular among people with disabilities, and their networks are making claims for inclusion to work in the Malaysian school system (Jayasooria et al., 1997). However, a study of Malaysian demographical trend by Annuar Maarul (1991) reviewed in Jayasooria et al. (1997) suggests that due to the changes from rural to urban society, there has been an increase in the number of women in the workforce, which is claimed to give a negative impact on people with disabilities, as women were traditionally domestic carers. He argues that having women in the workforce creates tension in the role of 'care'. Other experts disagreed with this gendered view and argued that the factors influencing disability exclusion instead involve medicinal care, educational methods and welfare support (Jelas & Ali, 2012).

Ian Tugwell (1992) observes that the lack of special services, especially education and vocational training, is often seen in developing countries. For example, when a person with a disability reaches adult age, they continue their lives at a disadvantage because of the lack of education and training with regards to employment. Furthermore, when they begin to live within the community, they become part of an 'underclass' society, without much hope of escaping the poverty trap. Their dependence on their family members and their inability to contribute

anything to the family budget means they are less valuable to a growing urban society (Jayasooria, 1999).

Zalizan and Manisah (2012) argue that Malaysia has an ill-conceived policy of inclusion as the transference of policy into practice is problematic at both community and school levels. In this regard delimited perspectives on special education become a barrier to inclusion (Jelas & Ali, 2012). Adnan and Hafiz (2001) instead argue that the exclusion of people with disabilities is a result of inadequate application of the education policy adopted by various government agencies in Malaysia and that the school practices are merely unsystematically planned.

Jamaludin's (2011) study expresses the concerns of experts in the Ministry of Education (MOE) in Malaysia. They had claimed to provide a full inclusion programme for people with disabilities including those with a high functioning and low functioning impairment. However, experienced teachers express concerns as to whether full inclusion is the best solution (Jamaludin, 2011). Alternatively, implementing 'pullout inclusion' can provide better educational services to students and benefit from a smaller student-teacher ratio. The MOE standards allow children who are ineligible for full inclusion in public school to be pulled out and placed in a CBR setting (Jamaluddin, 2011). Experts have shown that programmes provided in a CBR setting, detached from the mainstream school system, can successfully provide education along with therapy and rehabilitation for people with disabilities (Kuno, 2000).

Valuing people's initiative creates an active focus on service changes derived from a genuine desire, on the part of key stakeholders, to promote positive experiences in the lives of people with learning disabilities. A change of this magnitude would involve a broad range of stakeholders in a significant organisational shift. Such an organisational shift would take much time and effort, and requires trust and shared commitment (Owen et al., 2009). Sternberg (cited in Owen et al., 2009) argues that the process of change involves a concentrated effort that includes identifying the cultural problems within an organisation that stand in the way of change.

The dilemma in policy making and implementation in Malaysian education for persons with disabilities may correlate with the inadequate translation of policy, which may in turn lead to discrimination and unsystematic planning, as suggested by Jelas and Ali (2012). The issue of the culture of elitism, which revolves around education quality standards designed to maintain excellent examination results, plausibly further isolates people with Down syndrome (Jelas & Ali, 2012).

Disability issues in Malaysia are likely categorised as a complex and ‘ill-structured problem’. Disability issues in Malaysia are capable of eliciting very different perceptions and values (Horn, 1989; Mitroff, Mason, & Barabba, 1983). Singh (2008) identifies a significant challenge to disability issues in Malaysia lies in the lack of uniform professional and equality services by health welfare and the education department.

As Horn (1989) discusses, ‘Ill-structured problems concern the various people having very different perceptions. The perception incorporates the values concerning the people's nature, the people's causes, the people's boundaries, and the people's solutions. Those are the problems that bring out two or more points of view from the first mention of the problem’. The challenge in this study is in placing a Design Thinking perspective in a real life situation such as the development of social inclusion of PDS in Malaysia. Placing Design Thinking into a social studies context speaks of an interdisciplinary research approach.

To address an ill-structured problem, Checkland’s Soft Systems Methodology (SSM) will prove to be essential as a unique brand of action research. SSM represents the crystallisation of an interpretive-based systemic theory as well as the formulation of principles of action in ill-structured problem contexts (Flood, 1999). Chapter 3 focusses on the design model that contributes to illustrating the narrow aspect of social inclusion on PDS in Malaysia. The chapter comprises a review of each of the three strands of Checkland’s (1990) soft systems approach for exploring the development of social inclusion of PDS in Malaysia.

## **PDS rights to inclusion**

There is limited information on Down syndrome support in available in Malaysian scholarly journals. Research, therefore, has to refer to evidence from other societies as examples to help frame and understand the issue of Down syndrome exclusion in Malaysia. The importance of looking at the history of inclusion worldwide is to grasp an overall decision on disability policy making made globally which instantaneously influences Malaysia factors to exclusion and inclusion policy making. The exclusion and inclusion on Disability rights presents a dilemma in policy making in education. For example, the relationship between teachers, parents, and administrators involved in programmes for students with Down syndrome as well as the purpose and the foundation of teaching programmes (curriculum) thus becomes more intertwined.

In the US, the 'Healthcare Preventive Medical Checklist' (Thios, 1999) is used by parents and carers to monitor the health condition of the child with Down syndrome. Prepared in 1981 by Dr Mary Coleman, this medical checklist was the first systematic guide to PDS and the family that was widely implemented by the medical community (Thios, 1999). However, some individuals, families and communities (such as the case in Malaysia) are unprepared to recognise disability and seldom readily accept it (Singh, 2008). That attitude, in turn, introduces doubt into the social world of the individual and the community (Ali, M. M et al., 2006; Jayasooria, 1999; Jelas & Ali, 2012).

An important attendant issue needs to discuss at this stage: the question of who determines whether someone's life is worth living, especially if the society believes there is a right to live, but excludes PWD from the internal social relationship. By forbidding the community from dismissing people but permitting the withholding of life-saving intervention, PWD is in effect deprived the right to a particular quality of life (Narveson, 1995). The right to quality of life for a person with disabilities is sanctioned by law in Malaysia as in the Disability Act 2008;

however this is often not actualised in practice. To rethink an individual's value in contemporary Malaysian society is to determine whether the life experiences of people with intellectual disabilities are of value (Ali, M. M et al., 2006). Disability, regardless of whether it is 'high' or 'low' functioning, is far from being a medical problem that can be 'cured'. Disability is a fact of life central to people and their relationships (Bryant et al., 2011; Shakespeare, 2001; Stratford, 1994; Stratford & Gunn, 1996). It is a cultural and socio-political problem (Borthwik, 1996).

One of the objectives of the International Classification of Functioning (ICF) is to establish a common language of information on health and health-related conditions including disability. There is growing literature that involves evidence and policy insights on health, disability and rehabilitation especially in connecting to the low or medium resourced countries of the world (World Health Organization & World Bank, 2011). The inclusion of students with Down syndrome, however, can present problems for schools' assessment practices due to their overexpression behaviour. That is, having an extra T21 gene can cause a person to have distinctive biological features, including a highly sensitive behavioural personality, specific cognitive span and fragile physiological characteristics. In general, persons born with Down syndrome experience overexpression of the involved genes that would lead to increased production of 'excessive' behaviour (Kuhn, 2010).

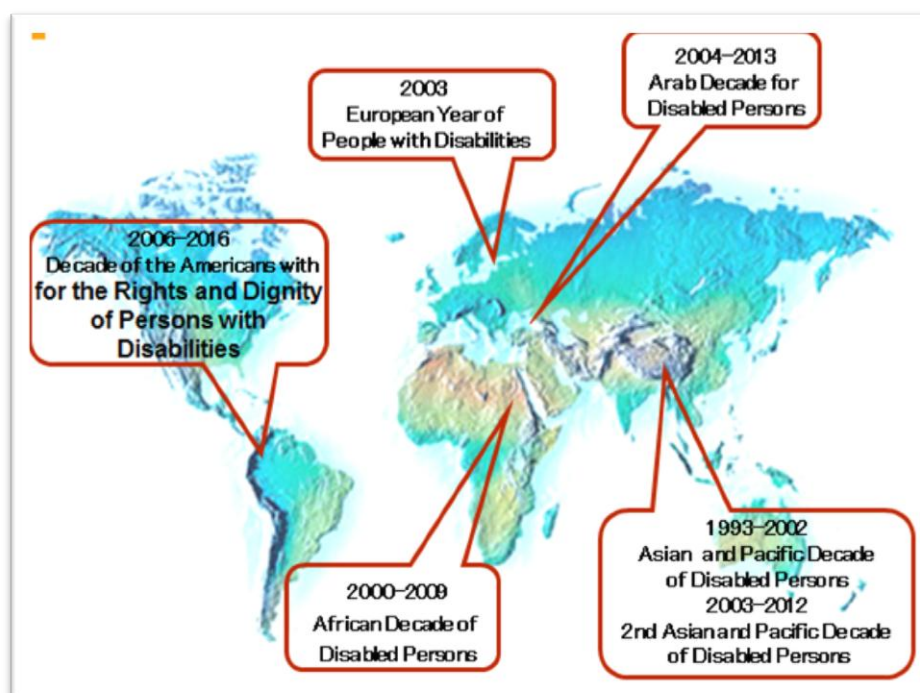
At issue here is the erroneous idea of locating the problem in the child and their impairment rather than recognising that it might be society's responses to the impairment that needs to change (Rieser, 2012). The No Child Left Behind Act of 2001 was modelled after the United States, which significantly aims to ensure all children have access to education support (Chapman, 2007). According to this law, the removal of institutional factors that support exclusion is an ethic-based right of all individuals. In the United States, this law requires all schools to make significant efforts to provide an inclusive education for every child (Skrtic, 1991). This in effect makes integration a civil right; if a child can be integrated then segregation is illegal, regardless of the school's integration philosophy (Ringer & Kerr, 1988). There are studies that suggest the responses of typically healthy children toward peers with a disability were often uncomfortable (Cottini & Nota, 2007). Some research in the United States also indicate that parents are cautious about inclusion and some fear

that other students would badly treat their child (Elkins, Kraayenoord, & Jobling, 2003; Savich, 2008).

There are also concerns that the negative perception of inclusive approaches to disability are driven by the motives of school administrations that are often more to do with budgetary measures rather than out of genuine interest for what is best for students in a classroom (Elkins et al., 2003; Savich, 2008). Students with a disability are required to meet specific scores in the core curriculum areas including maths, reading, writing, and science. Some teachers have expressed concern that students with disabilities can monopolise time and resources (Savich, 2008). In this regard, educators also face a dilemma regarding the curriculum and the need for teachers to achieve good average test scores often overrides commitment to students with a disability (Viglione, 2009).

Improving inclusion in collaboration with educational structures is therefore much needed (Baldacchino, 2012; Gadotti, 1996; Hick & Thomas, 2008; Wiggan, 2011). The drive to reduce exclusion in education has become a worldwide phenomenon because, traditionally, persons with a disability were more likely to be overlooked in schools and excluded from the education system (Stewart, 2005). Much progress has been made by the UN in standardising disability policy and reducing exclusion in education. Some regions of the world (i.e. European, America, Arabia, Africa, and Asia-Pacific), as well as individual countries, have also developed disability rights law in recent years (Weisbach, 2009). The emergence of disability law is likely to influence international human rights issues and concerns (McGuire, 2009). Figure 16 provides an overview of the known Decade of Disability Worldwide. This Figure provides a visual summary of the importance of Disability Policy and the differences of policy among different countries including Asian region. The listed laws may have different approaches worldwide, scope and content but they possess the same commitment to the rights of people with disability.

Figure 16: Global Situation on Disability (Yukiko, n.d)



The Decade of Disability has been acknowledged by all East Asian and Pacific nations as signatories to the United Nations Convention on the Rights of the Child (CRC). The idea that every child has a right to education is gaining strength within the Asia-Pacific region. The 'Asian and Pacific Decade of Disabled Persons' began in 1993 and was a significant step towards inclusive education in the region. Nevertheless, this model had to be supplemented by the International Classification of Functioning, Disability and Health (ICIDH) to address the functional perspective of social exclusion. This led to 'The Second Asia and Pacific Decade of Disabled Persons' in 2003 and, in the process, governments in the region made a significant commitment to ensuring education for children with disabilities (Price & Takamine, 2003).

The anticipated standardised language assumes that it would make it easier to compare conditions across nations, disciplines and sciences. The 'Rethinking Care' project was introduced by the WHO in 2001 (Barnes, 2001). This project adopted a holistic social and political analysis of disability and included the participation of people with disability that in turn generated several recommendations. 108



stakeholders from all over the world gathered for the Rethinking Care Conference comprising professionals and representatives of disability organisations, the majority of who had a disability themselves. The discussions at the conference generated 37 policy recommendations wherein the following positioning served as a key premise:

Health and rehabilitation can no longer be understood solely in term of orthodox medical interventions and orthodox notions of 'care'. These centre almost exclusively on the perceived limitations of individuals rather than on the society's failure to accommodate the needs of people with disabilities. Thus, there is an urgent need for an approach that cares not only about disabled people, but also about society and its structures (Barnes, 2001).

Oliver and Barnes (2012) acknowledge the agenda behind the initiative action project report and observe that social research is a political agenda: '... we must clearly recognise that all social research is political. Perhaps more importantly, consider the political function of the WHO and the World Bank in sponsoring the Report'. This statement suggests that decisions on disability issues might involve a political agenda and not necessarily a singular scientific approach. Oliver and Barnes (2012) continue by asking, 'Is social research on Disability Issues political or medical as some say?' As Bickenbach (2009) has argued, the scientific approach does not solve the problem the policy analyst needs to solve. He explains, 'If we restrict our scope to specific domains and severity levels, then our prevalence levels will differ accordingly. However, these decisions cannot be made conceptually or scientifically; they are political.'

The exclusion and inclusion on Disability rights presents a dilemma for the individual with a disability and the community. The focus on rights of education in the context of the lives of people identified with intellectual disabilities has not been prevalent in much of the research literature in Malaysia despite the development of local programmes (Adnan & Hafiz, 2001; Jelas & Ali, 2012). In examining medical and social debates concerning the right to life for persons with Down syndrome, experts find education in the broader community is the best therapy that allows inclusion of the intellectually disabled in social communities (Stratford, 1994). The right to life for a person with Down syndrome then becomes an educational issue.

The relationship between teachers, parents and administrators involved in programmes for students with Down syndrome as well as the purpose and the foundation of teaching programmes (curriculum) thus becomes more complex. Certain biological characteristics of people with Down syndrome are known to have poor behavioural development (Tickle, 2009). Unfortunately, teachers often identify such students as ‘naughty’ rather than managing their behaviour (Falvey, 1995; K. Smith, 2011). The complexity of mainstream placement results in less skilled teaching and group interaction. Adequate levels of resourcing are vital to focus on ways in which support is implemented (Buckley et al., 2007; Jayasooria et al., 1997; Leo, 1994).

## **2.3 INTERDEPENDENT PRAXIS**

This section will discuss the theoretical design model and interdisciplinary lens used for examining the development of social inclusion of PDS in Malaysia. This reviews the relationships and categorisations in a visual diagram because the visual diagram is especially useful both for conceptualising ideas and utilising as a memory device.

### **2.3.1 Understanding Design Research**

Kimbell (2011) suggests that professional design is now operating within an expanded and increasingly complex field of study. Design research with a particular interdisciplinary/ ‘transdisciplinary’ method can solve complex problems (Vianna, Vianna, Adler, Lucena, & Russo, 2012). For example, complex issues are analysed and synthesised to produce innovative solutions by means of user-centred approaches and multi-disciplinary teams (Bennett, 2006; R. Buchanan, 1992a; Cross, 1993; Dubberly & Evenson, 2011; Friedman, 2003; Ulla Johansson-Skoldberg, Woodilla, & Cetinkaya, 2013). An interdisciplinary or ‘transdisciplinary’ study, however, potentially places design research into practical and theoretical confusion. Accordingly, the context of the research is paramount in interdisciplinary or trans-disciplinary work (Love, 2000). Furthermore, if design research is confusing practice and theory, then design research processes need restructuring (Thoring & Muller, 2011). The influence of systems thinking and diagrams, for example, can spark

plausible holistic perspectives when viewed as a whole rather than the collections of parts as historically related to the Philosophy of Design.

Accepting design research as a way of thinking in the scientific field can be traced to the influential book *The Sciences of The Artificial* by Herbert Simon. The first edition was well-received in 1969. Robert McKim's (1980) *Experiences in Visual Thinking* was also significant and expanded the mechanical engineering curriculum that influenced Rolf Faste in Stanford Design School. The popularised notion of 'Design Thinking' has become one of the design research methods for creative action (Faste, Roth, & Wilde, 1993).

Design Thinking was originally a set of principles used in a different discipline as it was first adopted in business. In 1978, founder David M. Kelley developed Design Thinking as the motivating idea behind global design consultancy IDEO and the Stanford Design School (Levy, 2000). Design Thinking in the late 80s and early 90s was influenced by Peter Rowe's (1987) Design Thinking book, which was used by architects and urban planners. The principles of Design Thinking are discussed in Richard Buchanan's (1992a) article 'Wicked Problems in Design Thinking' which addresses intractable human concerns through design. Buchanan's (1992a) report expresses concern regarding design research theory construction.

Design research involves several fields as well as differing aspects and perspectives. One thing is nonetheless certain: design research has the capacity to extend across other disciplines. As Friedman (2003) writes, 'Design represents other domains of the design field. For example, in natural science, humanities and liberal arts, business, social and behavioural science, human professions and services, creative and applied arts, technology and engineering.' Originally, in the 1960s, design research emerged as a recognisable field of study with the key emphasis on developing work through design method at Imperial Collage London (1962). The founders of the Design Research Society (DRS) in 1966 included a process for design that was developed with the help of John Christopher Jones, founder of the postgraduate Design Research Laboratory in the Institute of Science and Technology at the University of Manchester (Jones & Thornley, 1963) and Bruce Archer, founder

of the postgraduate Department of Design Research at the Royal College of Art, London (Archer, 1969).

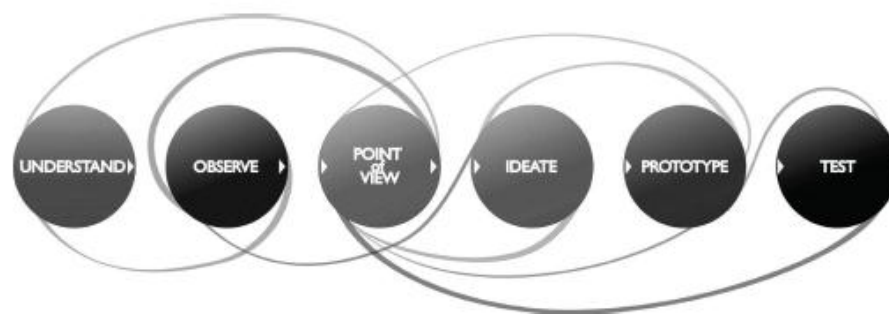
In order to understand design as a generalisable discipline, it is important to develop a general theory of design (Friedman, 2003). Simon (1996) defines design as the process which devises a course of action aimed at changing an existing situation into the preferred ones. Vianna et al. (2012) offer an example: ‘by taking the trouble to conduct a systematic survey, the designer can pinpoint the causes and consequences of difficulties and be more assertive in seeking solutions.’ As Vianna et al. (2012) claim: ‘Designers identify problems and generate solutions from them’.

Lawson (1990) cites Cross’s (1982) earlier study which posited that scientific problem-solving was done by analysis while ‘designers’ solve problems through synthesis. However, as Thoring and Muller (2011) argue, there are ‘numerous books and scientific publications about the topic of Design Thinking, but what is missing is a detailed and well-structured formal model of the actual method.’ Brown (2009) had stated that Design Thinking utilises both analysis and synthesis. Analysis and synthesis come from (classical) Greek words that mean "to loosen up" and "to put together" respectively. In general understandings about research, analysis is defined as the style of research which involves breaking down information into components. Synthesis is the opposite method in the research process which involves combining separate elements to form a logical body of knowledge. Nevertheless, analysis and synthesis, as scientific methods, always go together hand in hand. They complement one another. Ritchey (1991) suggests that every synthesis involves the results of a prior study. Every analysis needs a following synthesis in order to confirm and correct its results (Ritchey, 1991).

Friedman (2003) explains that Design Research often gets tangled between theory and practice, ‘The nature of design as an integrative discipline places it at the intersection of several large fields [so much so] ... that Design often confuses practice with research – instead of developing theory from practice through articulation and inductive inquiry, some designers only argue that the practice research and practice-based research is ... a form of theory construction.’ Design

Research that uses the Design Thinking model is nonetheless aimed at solving problems, meeting needs, improving situations, or creating something new or useful. Figure 17 is an illustration of the Design Thinking process model as a Design Research theoretical model (Thoring & Muller, 2011).

Figure 17: The Design Thinking Process Model (Thoring & Muller, 2011)



Importantly, however, Cross (1993) argues for simplifying the paradigm of Design Research with the effect of making Design Thinking a well-known topic in the field of Design and Innovation (Thoring & Muller, 2011). This repositioning consequently enables the development of theories in Design Research as a form of serious criticism (Love, 2000).

### **2.3.2 The concerns in Design research**

This literature review has so far concerned the development of the theoretical model for design research. This section will focus on evaluating this model.

First of all, how can design research interpret the raw data of a complex case such as the twinned issue of PDS rights and understanding barriers to social inclusion in Malaysia without positioning itself in a contextual ambiguity of ‘practice’ and ‘theory’? Such concerns have, as suggested by Love (2000), led to the development of theories concerning mixed methods in design research. Love (2000) recommends the importance of clarifying relationships between individual concepts and theories, and between these different concepts and theories and their underlying assumptions. Kimbell (2011) highlights a similar concern and further suggests ‘[t]here are some design professionals that take solving complex social issues as their domain, often

but not always working in close collaboration with specialists in public services from health care to those working with disadvantaged families.’

In 1984, Cross critically analysed Design Research and identified four overlapping themes, which also represent the chronological development of research into design. Cross (1984) identifies criteria relevant to the field of Design Research: [1] The management of the design process; [2] The structure of design problems; [3] The nature of design activities; [4] ‘Reflection’ on the fundamental concepts of design. However, Dixon (1989) argues there is ‘the confusion in design theory by regarding all Design Research as being in a pre-theoretic stage.’ Consequently, in 1993, Cross (1993) reported on topical theoretical developments that qualify his previous findings. He wrote, ‘The design movement started with the intention to make design more scientific, however as the field matures, design methodology has resulted in clarifying the differences between design and science (Cross, 1993). Cross’s 1993 study discusses the short history of Design Methodology and its relationship with science. He also maps some of the major themes that have sustained it and manages to establish some agreed-upon understanding of the concepts of scientific design, design science and the science of design.

At the same time, however, Love (2000) argues that Cross’s short history of Design Methodology is problematic in its suggestion of Kuhnian-style development. Moreover, the different sub-paradigms of design theory across all paradigms in Cross’s study creates further terminological confusion in the field of Design Research (Love, 2000). Love (2000) proposes that Design Research requires restructuring and states, ‘What remains needed is ... structuring existing concepts and theories to bind the unnecessary growth in abstraction and terminology ... so that it is clearer to a design researcher which concepts, theories and theoretical strands are pragmatically more useful or better justified, and what their relationships are to each other.’

Design thinking has subsequently developed to become a significant and accessible Design Research theoretical model. Ladner (2009) observes that design thinking is the new ‘It-Girl’ of management theory. He comments that it provides

managers with creative solutions to old problems. However, design thinking alone will not solve problems for innovation because lack of creativity was never the issue. Kimbell (2011) proposes that it is necessary to rethink design thinking in terms of three primary concerns: (1) As a cognitive style; (2) As a general theory of design; (3) As an organisational resource. Kimbell (2011) lists the different ways of describing design thinking as shown in a morphological table in Figure 18.

Figure 18: Different ways of describing design thinking (Kimbell, 2011)

**Table 1** Different ways of describing design thinking.

	<i>Design thinking as a cognitive style</i>	<i>Design thinking as a general theory of design</i>	<i>Design thinking as an organizational resource</i>
Key texts	Cross 1982; Schön 1983; Rowe [1987] 1998; Lawson 1997; Cross 2006; Dorst 2006	Buchanan 1992	Dunne and Martin 2006; Bauer and Eagan 2008; Brown 2009; Martin 2009
Focus	Individual designers, especially experts	Design as a field or discipline	Businesses and other organizations in need of innovation
Design's purpose	Problem solving	Taming wicked problems	Innovation
Key concepts	Design ability as a form of intelligence; reflection-in-action, abductive thinking	Design has no special subject matter of its own	Visualization, prototyping, empathy, integrative thinking, abductive thinking
Nature of design problems	Design problems are ill-structured, problem and solution co-evolve	Design problems are wicked problems	Organizational problems are design problems
Sites of design expertise and activity	Traditional design disciplines	Four orders of design	Any context from healthcare to access to clean water (Brown and Wyatt 2010)

Source: Lucy Kimbell

There are different ways of using the Design Thinking model (Kimbel, 2011). Nevertheless, it continues to be debated as Nussbaum (2011) succinctly puts it, 'Design Thinking itself has become a key issue.' Design Thinking initially offered large companies defined by a culture of efficiency a whole new process that promised to deliver creativity. Nussbaum (2011) agrees that these changes would not have occurred without Design Thinking. 'Humanistic Design' is an enormous advance in the field of social change facilitated, in part, by developments in Design Thinking (Shea, 2012). Examples include work by the 'Acumen Fund', 'Project H', Arson's students at 'Memorial Sloan Kettering', 'Stanford's K-12 initiative', IDEO

at the ‘Mayo Clinic’ and ‘Kaiser Permanente’, which would not have occurred without the approach of Design Thinking.

In 2013, Nussbaum proposed the emergence of Creative Intelligence. It is a concept derived from Design Thinking. He asserts that Design Thinking broke design out of its specialised, narrow, and limited base, and connected it to more important issues and a wider universe of profit and non-profit organisations (Nussbaum, March 2013). In comparison, Creative Intelligence expands that social engagement and frames problems in new ways by using low or high capacity intelligence to frame and solve problems. At any rate, creativity in innovation is not a new concept. In 2002, Theodore Levitt (2002) had previously written about creativity being the fuel of innovation. He expresses concern that creativity can be destructive to business when practical implementation fails. Levitt (2002) explains that ‘[c]reativity as it is commonly defined—the ability to come up with brilliantly novel ideas—can be destructive to businesses.’ He continues to explain that ‘... by failing to take into account practical matters of implementation, big thinkers can inspire organizational cultures dedicated to an abstract chatter rather than purposeful action. In such cultures, innovation never happens—because people are always talking about it but never doing it.’

So, how can Design Research interpret and edit the raw data of a ‘complex’ case study such as PDS rights and understanding barriers to social inclusion in Malaysia? Design Research involves organising the concern with reference to the efficiency of communication, the technology used, and the social responsibility at stake (Bennett, 2006). The primary concern of Design Research is to develop a clearer paradigm and to have pragmatically more useful or better-justified strands. The biggest concern is how to structure existing concepts and theories, and avoid unnecessary abstraction at the same time. A framework is needed which defines and expresses what constitutes knowledge about that situation. It can also help draw a distinction between research and novel writings and make the research recoverable. The framework that can support Design Research, as well as interpret and edit the raw data in this study, is Soft Systems Methodology (SSM). The processes in SSM



are recoverable by anyone interested in subjecting the work to critical scrutiny. The next section presents a review of Checkland's Soft Systems Approach.

### **2.3.3 The influence of Systems Thinking**

Systems Thinking and Design Research represent an interdependent praxis for interpreting and editing raw data in a complex case particularly in form of visual diagrams. Design Research provides an established approach which can be used to help understand the barriers for the social inclusion of PDS in Malaysia. Having a clear understanding of the practical and theoretical methods in Design Research is essential.

Systems Thinking includes both analysis and synthesis in problem-solving (Senge, 1990a). It seeks to sort information and group important data in a way to provide better understanding and support for the multiple disciplines of an organisation. Thus, Systems Thinking is necessary to this research because it is a suitable Design Research method to review the research data concerning the development of social inclusion of PDS in Malaysia.

Bruce Archer (1969) nonetheless argues that Design Research faces a major challenge. The challenge lies in the adaptation of systematic methods borrowed from computer techniques, which constitute a fundamental challenge to conventional ideas about design – specifically the advocacy of systematic methods of problem-solving, adopted from computer techniques and management theory, which are used for the assessment of design problems and development of design solutions. The growing advocacy of such systematic methods can be seen in examples from data visualisation (Friendly, 2009) and mapping information (Brightman & Banxia Software Limited, 2003) in the discussion to follow.

According to Friendly (2009), the method for problem-solving changes over time as newer information is discovered with the advancement of technology. A systemic method for problem-solving in data visualisation can be viewed dated back as early as the 17th century. In the context of the science of visual representation, data is

defined as information, which has been abstracted in a schematic form including variables for the units of information. Friendly (2009) have categorised examples of these problem-solving techniques:

- (1) **Early mapping and diagramming.** In 1305, mechanical diagrams of knowledge acted as aids to reasoning and served as an inspiration to Leibnitz in the development of symbolic logic, which was developed by Ramon Llull's (1235–1316) in Spain.
- (2) **Measuring and theory.** Visual representations were used to chart the changes in sunspots over time. The first known idea of “small multiples”, which show a series of images in a coherent display, was developed by Christopher Scheiner (1575–1650) in Italy.
- (3) **The new graphic forms, including a diagrammatic process developed to represent colour systems.** In 1758, Mayer developed a system of constructing and naming many of the possible colours. Lambert extended this with a 3D pyramid dictating depth (or saturation) as developed by Johannes Tobias Mayer (1723–1762), Moses Harris (1731–1785) and Johann Heinrich Lambert (1728–1777) in Germany.
- (4) **Modern data graphics in an increasing number of scientific publications** begin to contain graphs and diagrams which describe, but do not analyse, natural phenomena such magnetic variation, weather, tides and more as developed by Michael Faraday (1791–1867) in England.
- (5) **The golden age of data graphics** whereby social data diagrams including regional surveys are incorporated in museums as developed by Patrick Geddes (1854–1932) in Scotland.
- (6) **The modern age begins the development of modern statistical theory** such as sampling distributions (1915), randomisation and likelihood (1921),

small sample theory, exact distributions, and analysis of variance (1925) as developed by Ronald Aylmer Fisher (1890–1962) in the UK.

(7) **The re-birth of data visualisation** is the age where systematic graphical rational patterns for statistical presentation became common as developed by Roberto Bachi (1909–1995) in Israel.

(8) **High-D data visualisation made way for Sparklines.** Sparkline is a data-intensive, design-simple, word-sized graphic which is designed to show graphical information in line with text and tables as developed by Edward Tufte (1942–) in the USA.

Jenny Brightman and Banxia Software Limited (2003) have categorised examples of mapping information into four different methods dated back to the early 1990s:

- (1) **Mind mapping;** developed primarily by Tony Buzan (1993)
- (2) **Concept mapping process;** developed primarily by Joseph Novak and Bob Gowin (1984)
- (3) **Cognitive mapping;** developed primarily by Colin Eden (Eden & Achermann, 1998; Eden, Jones, & Sims, 1979), and further tutorial development by Fran Ackermann (Ackermann, Eden, & Cropper, 1992)
- (4) **Dialogue mapping;** developed by Jeff Conklin (2003), each of these methods provides a framework for structuring qualitative data (or ideas) into argumentation analysis

Typically, Design Research leads to ‘design making’ and in the context of Graphic Design, it often speaks of design as a process (Holland, 2001). Vianna et al. (2012) stated in *Design Thinking Business Innovation*, ‘After the data collecting stages ... the next actions are analysis, and synthesis of the information obtained ... [which is in turn] arranged to form patterns posing challenges that will assist in clarifying the problem.’ *Design Thinking Business Innovation* offers suggestions for

how future research may be conducted along these lines. The list of processes for analysis and synthesis includes Insight Card, Affinity Diagram, Conceptual Map, Guiding Criteria, Personas, Empathy Map, User's Journey, and Blueprint (Vianna et al., 2012).

Dubberly (2008) observes that the concept of design is expanding. This expanding concept of design creates an environment in which objects created by the designer can change. Dubberly (2011) states, '... this concept of design aims to sustain nature, humanity, technology and to illustrate harmonised cultural differences and distilling issues of the past, present and future into a dynamic balance.' However, what happens when Design Research is incorporated as part of an interdisciplinary study involving issues of social inclusion? The International Council of Graphic Design Association (ICOGRADA) has published its first Design Education Manifesto. The publication outlines many changes in the context of design practices and theory, and redefines them as visual communication for the future of design education (Dubberly, December 5, 2011; ICOGRADA, October 2000).

The context of design research in Graphic Design is also shifting. The shift is not focussed on what new knowledge is produced but how it is produced. This shift in worldview and framing influences change in organising structures from individual design to web design. The management of design education, be it in terms of 'top-down' or 'bottom-up' management, has to be responsive to this shift and embrace multiple knowledge (ICOGRADA, October 2000). Many design subjects have become trans-disciplinary. The issue of creating the object is linked to the issue of social experience while the need for creating products is related to a concern for networks of interaction and communities in a system. In addition, design research is experiencing a further paradigm shift with the advent of the Internet, as explained in Porter (1998) and Ess and Dutton (2013).

#### **2.3.4 Systems Thinking: in seeing the opportunity**

Multiple knowledge is discussed in Peter Senge's book, *The Fifth Discipline: The Art and Practice of The Learning Organization* (1990a). He writes, 'The

fundamental idea of an organisation exists within their surroundings. It is made up of interrelated, interconnected and complex knowledge that may consist of various experts of different disciplines working together.’ It is similar to having a large box filled with endless numbers of smaller and smaller boxes – each representing an organisation that in turn includes a large number of smaller and smaller ways of thinking.

Design Research has developed to account for such changing views. The subjective opinions held by designers and the concrete objects conceived, planned and produced act as expressions of those changing views (Buchanan, 1992a). The term ‘design’ is commonly associated with products’ quality or aesthetic appearance. Some even define the primary goal of design as a discipline is to communicate the quality of aesthetic appearance in people’s lives (Vianna et al., 2012). Nevertheless, according to Arnheim (1968), the designer’s way of looking at information is similar to the way in which a mind works as it analyses and synthesises information. But as Ritchey (1991) observes, ‘Careless interpretation of analysis and synthesis definitions has sometimes led to quite misleading statements. For instance, synthesis is useful because it creates wholeness or analysis is inadequate because it reduces wholeness to alienated parts.’ Buchanan (1992a) nonetheless believes that the ‘art of design is experimental thinking.’ Examples of successful research methods that involve seeing information as analysis and synthesis can be viewed in the works of William Playfair (Tufte, 1990).

Love (2000) argues that the problems in Design Research are mainly due to the unnecessary multiplicity of theoretical concepts. Popper (1976) likewise addresses the problem of theoretical confusion and validation. He provides an analysis of the relationships between the following three worlds. World 1 refers to physical objects and material things. World 2 is the subjective world of mental objects. World 3 relates to objective knowledge. Phillips (1989) analyses Popper’s Three Worlds. By referring to research on getting English native speakers to speak Russian, he provides an example illustrating one of the problems facing a design theorist who is attempting to formulate a well-justified theory about the internal creative processes of designers. He concludes that any theories regarding design

must involve both the material and subjective worlds. At the same time, however, the real test of theories in design lies in their validation and coherency. Theories related to design research need to be consistent with other well-supported theories across disciplines apart from the field of design (Phillips, 1989). The test of theories in design resides in whether they have broader applications and not restricted only to the area of design research (Love, 2000).

Joan Costa (2012) is an expert in visual communication who has written about the paradigm shift in design research in the context of graphic design. Costa states that ‘the notion of the project in Graphic Design will extend beyond the graphic to the visual dimension of being’. Graphic design products such as posters, logos, websites, packaging and way-finding boards do not simply signify things, rather they cause communication. According to Costa, everything requires communication and it is impossible to avoid the transmission of information without communication. Arnheim (1968), in his book *Visual Thinking*, maintains that the way people perceive information is also reflective of the way we think. Simon and Larkin (1987) examine how the brain seeks to make connections that generate meaning. Our eyes and brain work together to ‘understand’ what we see in our environment.

Senge (1990a) notes that being able to step back far enough from the details ‘to see the forest for the trees’ is to be valued. However, for most of us when stepping back, we still see lots of trees. When attempting to make improvements, we often simply choose our favourite ideas to focus our attention and efforts to provide change. The benefit of Systems Thinking in Design Research lies in its capacity for seeing through the complexity to the underlying structures generating change.

Design Research consists a set of elements, connected together, which as a whole form theoretical consistency. Appraising the properties of the ‘whole’ system rather than its component parts is recommended by Checkland and Poulter (2010). Systems Thinking sees interrelationships rather than linear cause-and-effect chains. It functions to comprehend the processes of change rather than snapshots of change (Senge, 1990b). The early Systems Thinkers were nonetheless over-ambitious in

their belief that the dynamics of a system could exist completely analysed (Flood, 1999). Barton and Haslett (2007) advocate ripping apart an element and analysing the pieces one by one, and by subsequently putting the parts back together again (or synthesis) one can arrive at an analysis of the issue as a whole.

Systems Thinking is a crucial component in sustaining research involving complexity theory and many of the insights that now labelled ‘complexity’ are classic systems concepts (Flood, 1999). Indeed, it considers how to intervene in a human activity system rather than defining human activity with complete accuracy (Flood, 1999). The insights supported by Soft Systems Thinking are often as useful as any. It is a system nested within systems and the interrelationships across an organisation. The problem situation must be taken into account when a change of intervention signifies planning (Flood, 1999). The change of intervention indicates that organisation-wide approaches are sometimes required. For example, an understanding of interdependencies of the discipline can be used to enhance the effectiveness of implementing change (Checkland & Poulter, 2010). Illustrating the network in visual diagrams is an important part of this type of research because they provide simplified, abstracted figures or caricatures to convey essential meanings (Hall, 1996).

At any rate, this process can be troublesome given the natural human tendency to avoid change, even when it is ultimately positive (Owen et al., 2009). Communicating information through Design Research can start a theory that exists before practice occurs, and practice may bring results after several attempts to obtain consistency (Friedman, 2001). It takes time to build on a theory in research and much longer to put it into practice, which will lead to a consideration of how theory might actually affect the rate of productivity/outcome.

### **2.3.5 Diagram: a decision making device**

According to Stephan Kosslyn (1980) and other cognitive researchers such as Blackmore (1999) and Dawkins (1976), perceptual senses mimic the way our minds work. Visually representing ideas such as relationships and categorisations in a

visual diagram can come close to how our minds naturally work. As a result of these attributes, a visual diagram is especially useful both for conceptualising ideas and utilising as a memory device.

According to Hall (1996), 'diagrams are usually simplified figures, caricatures in a way, intended to convey essential meaning'. Examples include graphs, technical illustrations, charts, tables and information visualisation (Brasseur, 2003). Brasseur (2003) noted that 'the features of a good diagram are style, transparency, ease, pattern simplicity, and validity. Diagrams rely very much on abstracted views, and the forms developed hold ideological consequences for designers and readers.' These issues need to be considered in any diagram was drawn by an individual to communicate a message. It will need some translation to communicate its message to the reader (White, 1984). In addition, if a diagram is arranged in particular ways and assigned with certain colours and sizes, the ensuing result is a visual that will take even more advantage of innate perceptual 'sense' making because diagrams are a prime device for persons or groups to use in decision-making (Brasseur, 2003).

Diagrams are essentially drawings with text. As Lowe writes, 'diagrams are abstract graphic portrayals of the subject matter they represent' (cited in Brasseur, 2003). Abstract graphic portrayals include such visual forms as flow charts. In other words, a diagram is any visual formatting device that does not display quantitative data and holds simple shapes connected by lines, arrows or other visual links. The visual formatting method consists of fundamental relationships and shapes that convey an idea. Some diagrams include realistic portrayals of life and others tend to show a basic abstract structure rather than a more highly contextualised view. Simon and Larkin (1987) ask the question: how difficult is it to solve a problem when using a diagram as opposed to using sentences? They present evidence-based research to support the claim that diagrams can be superior to verbal descriptions for solving some problems for the following reasons:



1. Diagrams can group together all information that is used together, thus avoiding the large amount of search for the elements needed to make a problem-solving inference.
2. Diagrams typically use location to group information about a single element, avoiding the need to match symbolic labels.
3. Diagrams automatically support a large number of perceptual inferences which are extremely easy for humans.

According to Simon and Larkin (1987), the pulley problem presented in their study is not logically complex, rather it is psychologically complex. Its major difficulty is that it is challenging to identify and describe one or more recently developed values in written sentences (Simon & Larkin, 1987). Thus, in their study, most people drew the problem in the form of a diagram because it allows information to be accessed and processed simultaneously.

## **SUMMARY**

As gaps in knowledge as discussed in this chapter reviews the importance of disability rights of PDS in Malaysia. However, Malaysia has a relatively recent history of 'inclusive education'. The advocates concerns on inclusive education in Malaysia was reviewed that discussed PDS rights to inclusion and the importance of understanding the history of inclusion worldwide to transfer disability policy into education.

This research therefore aims to present, through visual diagrams aimed at the disability sector in Malaysia, information which can provide potentially positive future outcomes (in terms of skill development and their right to education) for people with Down syndrome. This research will gather material of data with the focus on the main objectives.

In the next chapter will look into how can Design Research interpret and edit the raw data of a 'complex' case situation such as Person with Down syndrome (PDS) rights and understanding barriers to social inclusion in Malaysia? There are

two research objectives of this study. One is an analysis of a theoretical design model that explores the development of social inclusion of Persons with Down syndrome (PDS) in Malaysia as a case study. The second is a design model that contributed to data findings illustrating the narrow aspect of social inclusion for Malaysian people with Down syndrome.

## **CHAPTER 3**

### **Research Methodology**

#### **3.1 INTRODUCTION**

The significance of this study is the therapies and rehabilitation programmes has possibilities for overcoming exclusionary barriers of PDS to participation in society in the form of disability arts that disability arts education has the potential to succeed because of its value as a form of conceptual critique and point of difference in playfully and pragmatically arranged programmes.

The goal of Chapter 3 is to demonstrate in detail how this study has been conducted. Specifically, the design of the study is outlined, followed by a discussion on the research sample used in the study and how it was determined. This chapter also details the data collection process, as well as the process of data analysis. Furthermore, the chapter also touches on the issue of validity and reliability that is very vital in any study, and represents one of the most important components of this research. Finally, this chapter addresses the issue of the researcher's bias.

. The principal researcher did not have direct contact with PDS. This is because the principal researcher is not a medical expert and does not have the rights to interview PDS. Therefore, only parents, carers, and the people in the network of support for persons with a disability (PWD) could be included in the interview sessions.

### **3.2 DESIGN OF STUDY**

The design of a study is the framework for research utilised in the collection and analysis of data. It denotes the essential organisation of a study (Gay & Airasian, 2003). In this study, the design is based on qualitative research. This type of research builds on categories that emerge directly from participant data (Silverman, 2000). Qualitative researchers assume that "reality is socially constructed, complex and ever changing" (Glesne & Peshkin, 1992). As a result, meaningful categories must evolve from the context being studied. The researcher's role in a qualitative study is not to test a pre-formed hypothesis, rather it serves to determine and assess the social environment composed of the world around various participants (Glesne & Peshkin, 1992).

The researcher has chosen a qualitative research approach because it matches the objective of this study. The researcher wanted to analyse a theoretical design model by identifying characteristics of existing potential approaches to the use of a programme that can help reduce exclusion in the education of persons with Down syndrome (PDS). Also, this model contributes to illustrating the narrow aspect of social inclusion on PDS in Malaysia. As a result, the researcher decided to adopt a qualitative approach for this study.

The study started by implementing Qualitative Design and Design Research in an interdisciplinary context. The focus was on the empirical study of Objective 1 – An analysis of the theoretical design model (a) to identify an approach that can best demonstrate the characteristics of systems designed to reduce exclusion in the education of PDS; and (b) to understand the existing strategies for improving skills for PDS. The focus was on implementing Design Research and Soft Systems Methodology (SSM) for justifying the visual diagram in Objective 2. The Design Model contributes to illustrating the narrow aspect of social inclusion on PDS in Malaysia too (a) identify Malaysian structures that align with the education and empowerment of PDS through the use of a visual diagram; and (b) evaluate the consequences of design model decisions in explaining the complex situation of disability issues for PDS in Malaysia.

The combination of the SSM framework with design research is aimed at providing insights into the development of social inclusion of PDS in Malaysia. As Checkland had stated, (4:42 -4:54) 'Methodology is not the method. It is the logos of method, a set of principles, which in every use has to be crafted into a method which is appropriate for these particular people on this particular occasion' (Lancaster University Management School, 2012).

The methodology will consist of a theoretical and an empirical study that will be very closely linked together. SSM concentrated on the researcher method and how the researcher was able to use the method to get the best possible focus on the problem at hand (Checkland & Poulter, 2010). The empirical approach required qualitative research with mixed purposeful sampling, which mostly involves semi-structured interviews and the study of documents.

### **3.3 SAMPLING**

#### **3.3.1 Mixed purposeful sampling**

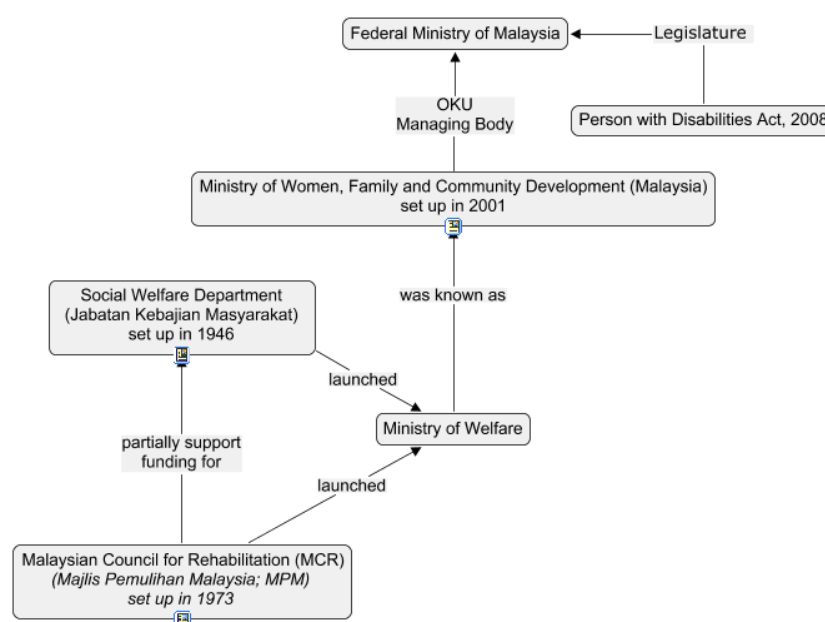
Mixed purposeful sampling is a combination of purposeful random sampling and snowball sampling strategy (Huberman & Miles, 2002). This type of sampling joins multiple interests and needs. Firstly, purposeful random sampling will look at a random individual. The strategy attaches credibility to a sample when the potential purposeful sample is larger, as suggested in Onwuegbuzie and Leech (2007). The approach is a type of random sampling that uses a small sample size. Thus, the goal is credibility, not representativeness or the ability to generalise.

Secondly, a snowball sampling will select the case problem of interest from the participants of the research. The process of a snowball (or chain) sampling will start from a person who knows another person, who knows what cases are information-rich, and who would be a good interview participant (Onwuegbuzie & Leech, 2007). For example, the research study may use this sampling to identify extreme or deviant case problems. That is, the research study might ask people to

identify cause problems that would be considered extreme/deviant and to do this until the study has consensus on a set of case problems that would be sampled.

When determining sample size for qualitative research, it is important to remember that there are no hard and fast rules. The estimated sample sizes are based on the data collection method used. The estimated sample size recommended by much qualitative study is 20-30 people. It is typically enough to reach saturation within a 20-40-minute interview session. Moreover, research shows that after interviewing the 10th participant, researchers often realise that there are no new concepts emerging. Thus, having a larger sample could begin to be redundant (Guest, Bunce, & Johnson, 2006). This research study began by identifying one influential participant who is involved in the managing body of Private and Public disability support services in Malaysia and subsequently expanded its scope through mixed purposeful sampling. Below in Figure 19 is an overall view of the purposeful random and snowball sampling.

Figure 19: Managing body (Disability support in Malaysia)



## Interview

According to Roulston (2011), qualitative interviews can potentially proceed at a tangent from the initially planned procedure. This may lead the researcher to deal continuously with challenges that arise during an interview (Roulston, 2011).

Gill et al. (2008) explain that an interview process serves to explore the opinions, struggles and beliefs of individuals in a particular situation. The process of interviewing aims to try to understand what people think through their speech. There are different types of interviews in conducting a qualitative study. For example, Gill et al. (2008) provide a range of research interview examples. It comprises interview procedures in accordance with structured, semi-structured and unstructured methods (Gill, Stewart, Treasure, & Chadwick, 2008).

This study conducted semi-structured interviews with a sample size of 29 participants from the groups listed in Table 1. Although semi-structured interviewing follows all the principles of unstructured interviewing, the informants are not expected to move too far beyond the scope defined in the interview guide (Barriball & While, 1994). In the beginning, a few non-structured interviews were conducted to get a better understanding of how the participants manage PDS for inclusive education. Local participants were interviewed in a conventional face-to-face manner (Kumar, 2006). Participants located at a distance were interviewed by telephone. The focus of these semi-structured interviews was to identify detailed concerns and factors relating to the establishment of a clear brief that expresses inclusion in education strategies and intellectual disability rights resources. The principal researcher did not include with PDS in this research study. This is because the principal researcher is not a medical expert and does not have the rights to interview PDS. Therefore, only parents, carers, and the people in the network of support for persons with a disability (PWD) could be included in the interview sessions. That also included the participants involved in providing the snowball sampling (chain sampling), previously discussed in the context of mixed purposeful sampling.

Interview data was collected between January and December 2011. Interviews were conducted in Malay and English. All interviews of this research study were tape recorded, and verbatim responses to semi-structured questions were translated and transcribed by the principal researcher, using a standardised transcription protocol. Transcripts were reviewed by the principal researcher for rendering the accuracy of the transcripts and revised them when required. Thematic

analysis was conducted on the translated transcripts using narrative analysis (Riessman, 2008). According to a study by Guest et al. (2006), a thematic saturation the point was to emerge from the twelfth interview. It was determined by the observation that the same central case problem was being reported by multiple participants and that no significant new data appeared.

**Table 1: Participant Setting**

<b>Malaysia</b>
<ul style="list-style-type: none"><li>• Taman Sinar Harapan, Cheras (TSH)</li><li>• Pemulihan Dalam Komuniti, KL (PDK)</li><li>• Persatuan Sindrom Down Malaysia, Ampang (PSDM)</li><li>• Kiwanis Down syndrome Foundation, Subang (KDSF)</li><li>• Cheshire Home, Gombak</li><li>• Independent Families</li></ul>

Data was gathered in Malaysia from the selected organisational setting participants in Table 1 above. The types of participants were categorised in Table 2 below. The questions for the interviews comprised a combination of open-ended questions listed in Table 3 below. These questions were designed to gather generic data in order to identify broad-based design contextual factors that related to broad-based organisational design drivers and limiting criteria.

**Table 2: Participant Groups**

<b>Participant Groups</b>
<ul style="list-style-type: none"><li>• Teachers</li><li>• Carers</li><li>• Parents</li><li>• Social workers</li><li>• Service Providers</li><li>• Volunteers</li><li>• Medical Professionals</li></ul>

**Table 3: Data Instrument**

Main and associated research questions	Information required	Questions - Semi Structured interviews
Step II →	Step III →	Step IV
What are the existing activities used to support people with Down syndrome in organisation in Malaysia? How effective is the methods.	Responses on the existing activities in Malaysia. Responses of DS to the existing activities.	Q1.1 Tell me about yourself? / What does your organisation do? Q2.1 What kind of activities do you use in your program? Q2.2 How often do you use the method? Q2.3 How effective is the method for achieving inclusion? Q2.4 How responsive are persons with Down syndrome to the strategies and methods that you use? Q2.5 How well do you feel your activities are implemented?
What existing effective activities used to improve skill for DS in Malaysias?	Responses on skill improvement activities in Malaysia	Q3.1 What other methods do you use to support inclusion education for people with Down syndrome? Q3.2 If so, how often? Q3.3 Is it Valuable? Q3.4 Why and Why not? Q3.5 Do you use Art in your program?
What effective activities that align with DS specific development characteristics?	Responses on learning activities that align with DS characteristics. Intensive Litreview and interview in australia	Q4.1 In your opinion can people with Down syndrome do art? Q4.2 If so, what forms of art do you think are best suited to their learning style? Q4.3 In your experience, what has led you to this decision?
How to include important data for stakeholders?	Responses on emancipating person with Down syndrome	Q5.1 In your experience, have you found that problem solving skills that they learn through art, they can apply them in a different setting or in a different task? Q6.1 Does your program support people with Down syndrome to have employment? Q7.1 Anything else?

## Study of Documents

The study of documents can refer to all kinds of written records such as government policies, educational legislation and requirements, education plans, demographic trends, teaching plans and student health records. Various organisational bodies compiled these written records, which are in turn meant for sharing with others in the public domain (Atkinson & Coffey, 1997). Bowen's study outlined the uses of public documents ranging from their advantages to their limitations. As Bowen (2009) states, the study of documents is a procedure for reviewing documents that can be in the form of print and electronic materials. These documents that were studied contain text (words) and images that were previously recorded without this researcher's involvement.



The evidence found in the documents was combined with data from interviews. The material found to be of relevance to this thesis, displayed in Table 4 below, were obtained from Public and Private Support services. Publications on Malaysia's disability services and programmes were identified based on library and web-based searches, as well as recommendations from stakeholders. For the purpose of this research study, evidence in the form of cultural artefacts themselves is not included because the analysis of these documents contributed to the literature review, as well as the mapping of Malaysian disability support services.

**Table 4: Public and Private support services**

Services	Public	Private		
	<b>PDK - Lembah Pantai</b>	<b>TSH - Cheras</b>	<b>PSDM - Ampang</b>	<b>KDSF - Petaling Jaya</b>
Programs	PT	PT	ISP	ISP
	OT	OT	TP	TOD
	ISP	SEP	PT	PT
	Community programs	Vocational programs	Parental Kit	Parent support group
Activities			Volunteers support Thematic Program Cooking Assessment	Volunteers support Cultural Day  Assessment Graduation
Category	Day care	Hostel Care	Day Care	Pre-Kindergarten
Definition				
ISP	Infant Simulation Program			
EIP	Early Intervention Program			
PT	Physical Therapy			
TP/TOD	Toddler Program			
OT	Occupational Therapy			

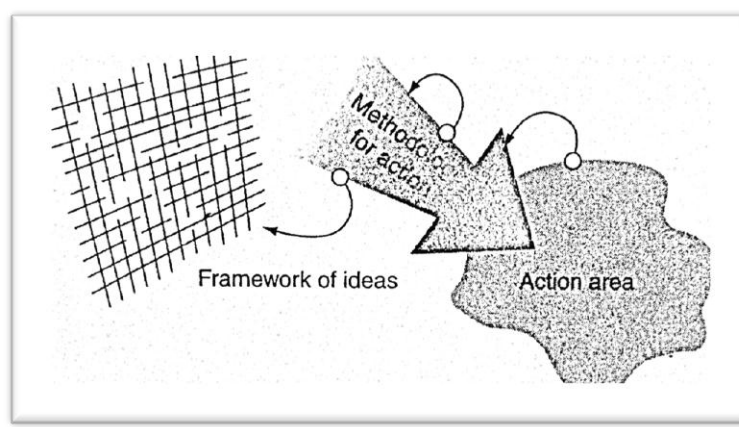
## **Qualitative Analysis**

The data collected in Qualitative Analysis are collected with the Design thinking model (Vianna, 2012). In his book *The Science of the Artificial*, Simon defined an early model of the design process, consisting of five stages: Empathise, Define, Ideate, Prototype, and Test. At the beginning of the Design Thinking, which is [E]mpathise where the principle researcher would explore the possibilities to experience the users environment, situation and concerns. The data collection will use research methods such as observation, interaction and interview. Next, is [D]efine, in this stage data collected is synthesised to form a user point of view that would be addressed and saturated into themes. Vianna et al. (2012) stated in Design Thinking Business Innovation, ‘After the data collecting stages ... the next actions are analysis, and synthesis of the information obtained ... [which is in turn] arranged to form patterns posing challenges that will assist in clarifying the problem.’ Afterwards, is [I]deate, a process where the principal researcher explores the possible solution through generating and explore possible perspective. Later, is to [P]rototype the data that will transform the idea into a physical form that can be experienced and interacted that can be learned and develop more empathy. Vianna et al. (2012) offer an example: ‘by taking the trouble to conduct a systematic survey, the designer can pinpoint the causes and consequences of difficulties and be more assertive in seeking solutions.’ As Vianna et al. (2012) claim: ‘Designers identify problems and generate solutions from them’. The prototype stage is where the principal research would visualise the data. In this research study, the principal research will use diagrams to visualise the collected data. The primary goal of design as a discipline is to communicate the quality of aesthetic appearance in people’s lives (Vianna et al., 2012). Lastly, is to [T]est the data. This stage is the process to refine the prototype and learn more about the user and to refine further the collected data. At this end stage, the principal research will go through Soft System Methodology (SSM) to test the data in the systems thinking procedure.

### **3.4 SOFT SYSTEMS METHODOLOGY (SSM)**

The concept of SSM was developed by a Professor of Systems at Lancaster University, Peter B. Checkland, in the late 60s (Flood, 1999; Lancaster University Management School., 2012). According to Flood (1999), action research led Checkland to appreciate the character of mechanistic and biological based systemic thinking. Action research involves the interrelationship of the framework of ideas, methodology for action and the action area (see example in Figure 20). The discussion that follows references Flood's (1999) analysis of Checkland's theory as outlined in three key books: [1] *Systems Thinking, Systems Practice* (Checkland, 1981); [2] *Soft Systems Methodology in Action* (Checkland & Scholes, 1990); and [3] *Information, Systems, and Information Systems* (Checkland & Holwell, 1998).

Figure 20: Action Research (Flood 1999)



#### **3.4.1 Action Research in interpretive-based systemic theory**

SSM started the study of Action Research in conjunction with interpretive-based systemic theory. Both ideas became key features that led to the establishment of principles for action to research ill-structured problems that Checkland had labelled as Soft Systems Methodology (Flood, 1999). Checkland applied action research principles to a programme of research in management science and systemic thinking (Checkland & Poulter, 2010).

Checkland's SSM technique was initially derived from Kurt Lewin's study on action research in the 1940s, which were first summarised as a collaborative process between research and people in a situation. The research process includes critical inquiry, which places a focus on social practices. The process is a deliberation on reflective learning (Adelman, 1993). These terms were needed to define and express the constituted knowledge about a problem situation.

Checkland (1985) recommended that such thinking be an essential form of reasoning for action research. The essential form of reasoning was assumed to help draw a distinction between research and novel writing and to make the research recoverable to anyone who is interested in the study (Flood, 1999). It includes processing [1] a framework of ideas, [2] a way of applying these ideas, and [3] an application area.

Interpretive thinking in interpretive-based systemic theory is a reflection of soft systems methodology through the principles of action suggested (Checkland, 1981). It recommends participation by all participating stakeholders. This idea is to rationalise that the term 'understanding' does not just arise from observation or theory. The possibility of understanding human behaviour lies behind each action (Checkland & Scholes, 1990). For example, a simple gesture such as smiling to a stranger or slapping somebody on the back might be interpreted as a friendly or hostile action respectively.

Flood (1999) explains the necessity to progress beyond observation and theory in interpretive thinking to achieve an authentic explanation of what is going on in the minds of people. This is because observation or theory does not provide sufficient learning and understanding to appreciate what is happening in the action area. To achieve interpretive-based systemic understanding, both the cultural characteristic in a situation and the interpretation and perception of the individual within the cultural context must be taken into consideration. Accordingly, interpretive thinking becomes systemic because it helps a particular study to become involved in seeing people's lives as a whole. It does so by uncovering meaningful

terms of social rules and practices, and the fundamental underlying meaning (Flood, 1999).

### **3.4.2 Hard and Soft thinker**

SSM is a Systems Thinking application originally understood as a modelling tool (Williams, 2005). SSM involves applying systems thinking to a non-systemic situation (or qualitative situation) such as social, political or human activity contexts by using a similar approach to how engineering systems are tested (Flood, 1999). SSM distinguishes itself from hard systems approaches in the way it deals with the notion of systems (Checkland & Poulter, 2010). In *Systems Colloquium* (2012) Checkland argues:

That within the human sphere we cannot make a sharp distinction between theory and practice. The ideas in one's head cause the person to have the experience we have in the world, but ultimately the experience in the world is the source of the ideas. So within the human world people are constantly in a hermeneutic (concerning the interpretation, especially of literary text) cycle, between the ideas and the experience of using them.

Traditionally, hard systems' thinking has been applied to engineering. It deals with physical objects. This approach is very useful in dealing with problems that are quantifiable. However, it has problems taking into account unquantifiable variables such as options, culture and politics and does not take into account that people can have rather complex motivation factors (Bjerke, 2008). Soft systems thinking, when applied to human action studies, developed as a way of dealing with problems that the hard systems approach had difficulties in accounting for, namely, problems that cannot be easily quantified. Soft systems thinking is useful for understanding motivation, viewpoints and interactions, and addressing both qualitative and quantitative dimensions of the situation (Bjerke, 2008).

At the same time, however, it is commonly misunderstood that SSM only deals with 'soft situations', for example, case problems that involve psychological, social and cultural elements (Forrester, 1992). However, Checkland explains that

SSM does not differentiate between soft and hard problems. Instead, it provides a different way of dealing with situations perceived as complex situations (Checkland & Holwell, 1998). In *System Colloquium* (2012) Checkland references Aristotle:

There will always be different world view...whenever groups of human beings gathered together, separate interest will be perused and that he Aristotle invented the word Politic as a way of coping with that situation. However, worldview is not fixed, worldview change. In a human situation, there are always different world views, and these are never static – it changes.

### **3.5 DATA ANALYSIS TECHNIQUES**

Narratives within groups are used to identify stories that may mobilise others and that can foster a sense of belonging (Riessman, 2008). The identified individual narratives from this research study may be variously in the form of argument, justification, persuasion, and even mislead an audience. The narrative analysis section in this research study was applied to identify the SSM Stage 1 Problem Situation. Data analysis in this research study suggests narrative analysis can identify problem situations with the application of the SSM 7 Stage Approach. SSM was used to analyse the 'real world' and the 'conceptual model' of this research study to produce a visual diagram. SSM was chosen for this study, firstly, because of the need to understand narratives that are active within the interviewed organisations. The narrative analysis visually formed a conceptual model of diagrams. Secondly, after the structures were identified and the ideal process visualised, the researcher could then decide on recommending possible solutions to suit the current and future needs of the interviewed organisations (Bjerke, 2008).

The conceptual models are not exclusively descriptive or normative. However, they may carry both components (Williams, 2005). When applying the SSM 7 Stage Approach to a research analysis, the researcher can structure 'thinking about the real world'. Although SSM conceptual models are not supposed to characterise the 'real world', nevertheless the 7 Stage Approach must be understood as a learning cycle, even when explained in a linear writing style (Flood, 1999).

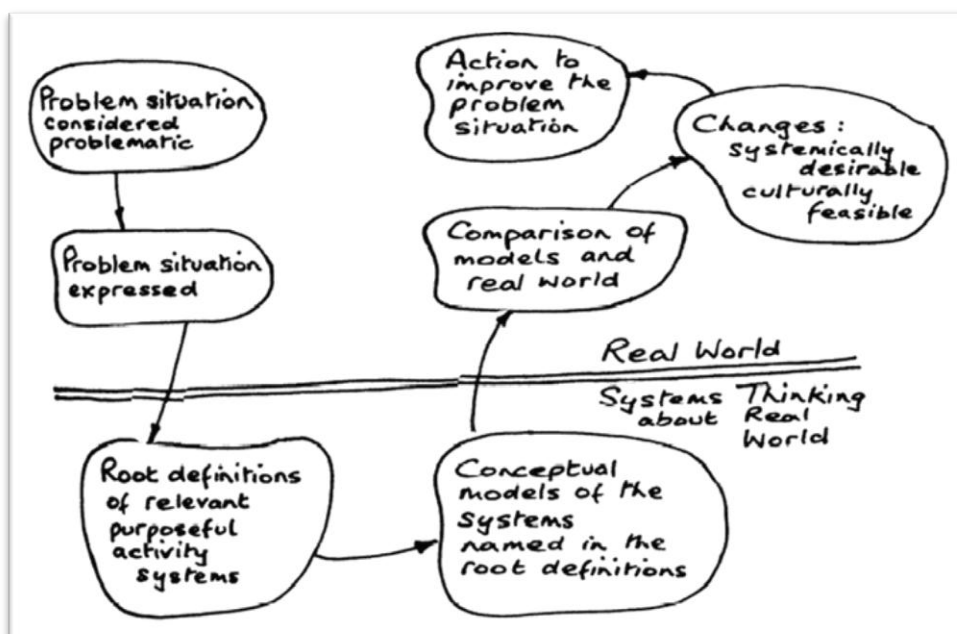
### **3.5.1 Checkland's Soft Systems Approach**

There many other systems approaches explained in Flood's study (1999). Nevertheless, the systems approach in SSM is the process to expand thinking. Checkland and Poulter (2010) consider the process of developing thinking to be one of the exciting outcomes of SSM. For example, the SSM model contains a comparison between the worlds as every person understands it with the conceptual models of the worlds as it might be. The types of comparison in SSM can result in a better understanding of the world as 'research', and offer some ideas for improvement through 'action' (Checkland & Holwell, 1998).

When Checkland undertook the SSM study, he was aware of the difficulty when formulating the 7 Stage Approach. The 7 Stage Approach was originally published in Checkland's book *System Thinking, System Practice* (Checkland & Scholes, 1990). It acted as a set of pedagogical tools concerning the rules and principles for SSM (Flood, 1999). However it came to be seen as somewhat outdated, therefore a considerable effort was made to describe the visual diagram as a *continuous* process of learning, as explained in a later publication by Checkland and Poulter (2010).

The 7 Stage Approach is still widely used and taught in soft systems study because SSM is designed to make it readily teachable (Checkland & Poulter, 2010; Williams, 2005). Most importantly the model, as shown in Figure 21, describes the seven stages with a bar that runs across between them. The bar serves to differentiate the stages between the 'Real World', above the line, and 'Systems Thinking' world, below the line (William, 2005). The figures in the visuals are understood as a learning cycle, even when explained within a linear form (Checkland & Poulter, 2010; Williams, 2005). The dynamics of the seven stages process are concentrated on Stage 2 through Stage 4 because these stages are always an iterative process (William, 2005).

Figure 21: SSM 7 Stage Approach (William, 2005)

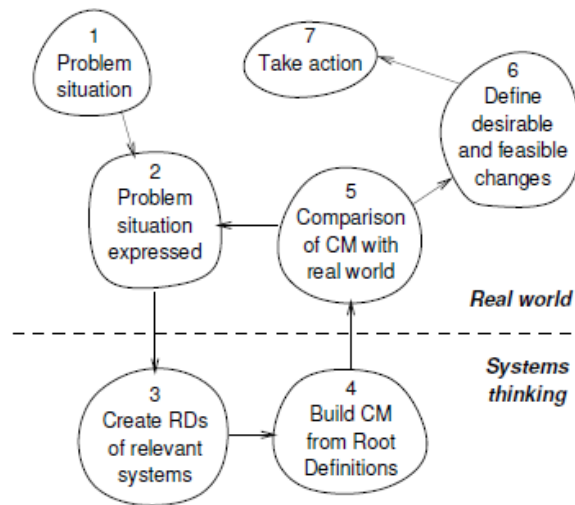


### 3.5.2 Overview of SSM 7 Stage Approach

SSM helps formulate and structure thinking about problems in complex, human situations. Thinking about problems involves the construction of conceptual models and the comparison of those models with the real world. As suggested by SSM experts, the 7 Stage Approach process can considerably clarify a multi-faceted problem that may contain too many conflicting potential solutions. Figure 22 outlines Checkland's Soft System Methodology (Checkland & Poulter, 2010).



Figure 22: Outline of the Checkland methodology



## Stage 1 – Problem Situation

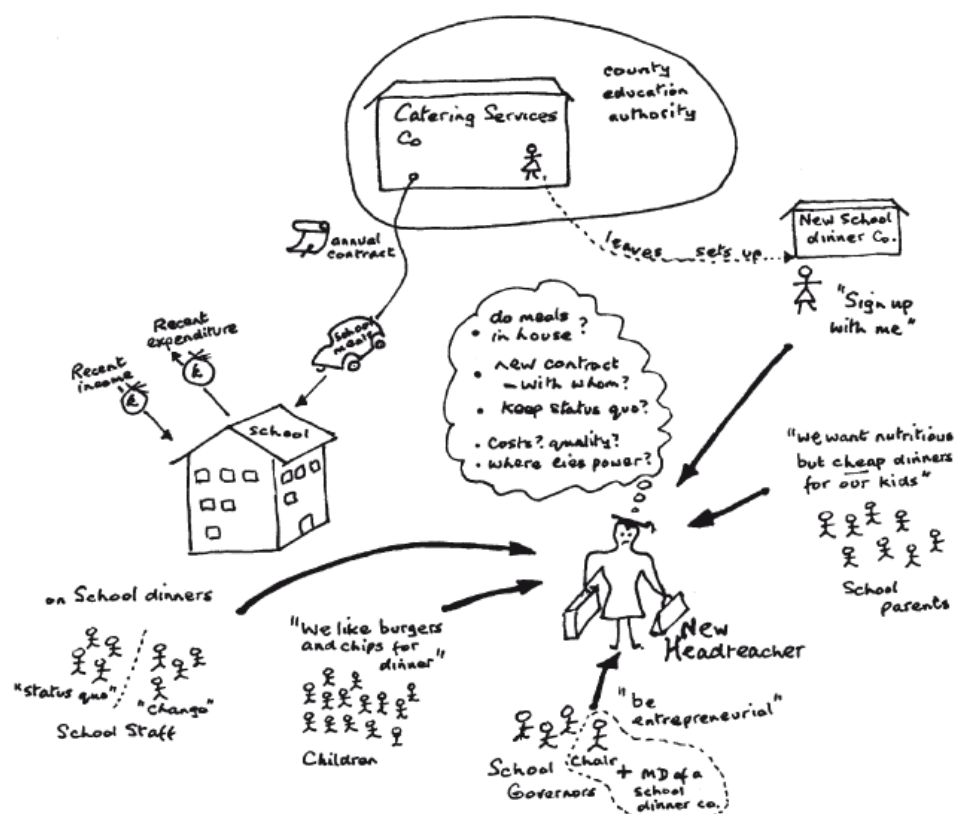
The first phase identifies the problem situation, very much expressed in terms of the real world situation. It serves to acknowledge, explore and define the situation that might arise from a number of people, for example, the case of feeling uncomfortable or concerned. In aiming to study the situation with a view to making some improvement, Checkland describes the ‘Problem Situation’ as the original purpose of developing SSM because SSM is a problem-solving methodology.

## Stage 2 – Rich Picture

In Stage 2, the problem situation is represented through the ‘rich picture’. Checkland has developed this technique to describe the real world situation. The case problem is drawn in a visual diagram as a way of expressing the relationships in a situation. Even though the rich picture may be seen as a pictorial extension of Tony Buzan’s (1994) drawings, it actually predates them (William, 2005). Rich pictures can be supported as a suitable medium of expression. The rich picture constitutes an attempt to avoid restructuring the problem situation in Stage 1, which would have confused the initial thought or original thinking. Checkland’s view on the system’s prototype as described in the rich picture is to assume the possibility for articulating the case problem through an imaginative procedure.

Checkland refers to the visual diagram as a 'rich picture' for two reasons. Firstly, the situation in any given case problem needs to be expressed in all its richness. Checkland includes guidelines about the type of factors required to show all the richness in case problems. For example, these factors involve structures, processes, climate, people, and issues represented by people's conflicts. Secondly, Checkland suggests that the best way of expressing case problems is via representing its richness in a pictorial form. Figure 23 is an example from one of his books that represents the rich picture of a distance learning situation.

Figure 23: A rich picture of a situation described in text (Checkland & Poulter, 2010)



### Stage 3 – Root definition of relevant systems

The transition into Stage 3 is made by naming possible human activity in the system. This Stage may offer insight into the case problem situation and may generate debate leading to action to improve the problem circumstances. This Stage addresses the human activity system, which is a systemic model of the activities people need to engage in so as to determine the direction or purpose for that pursuit. Stage 3 moves

out from the real world and into the world of systems. It is the stage where everything in a problem situation begins. Checkland calls Stage 3 the "root definition". It is a relevant, unique and most challenging part of the methodology.

Any real world situation can be viewed from many different angles. The number of systemic representations of the 'real world' that might be constructed by a researcher may be infinite. It is, consequently, necessary to identify what might be a relevant system. 'Relevance' is a subjective concept, which is why Checkland suggests the researcher identify several potentially 'relevant systems'. Eventually, the relevance will be tested when the analyst returns to the real world in Stage 5 to make comparisons in the visual diagram.

Having identified several relevant systems, the researcher then creates a 'root definition' (RD) of the system. It tested against a CATWOE analysis. As Checkland suggests, it is often useful to begin with 'root definitions' of several 'relevant systems' but only develop one ultimately. The Lancaster team headed by Checkland had recommended particular standards that should be defined to ensure the root definition is rigorous and comprehensive. These rules are summarised in the CATWOE (which is also applied when identifying the root definition).

### **CATWOE**

The model provides the mnemonic CATWOE, defined in Checkland & Poulter (2010, p.221). The concept here is that purposeful activity, defined by a transformation process and a worldview (a T and a W):

- Will require people (A) to do the activities which make up T
- Will affect people (C) outside itself who are its beneficiaries or victims (C for 'Customers')
- Will take as given various constraints from the environment outside itself (E) (such as a body of law, or a finite budget)
- Could be stopped or changed by some person or persons (O) who can be regarded as 'owning' it

CATWOE is a form of checklist for thinking. Like many checklists, it can be surprisingly useful when used appropriately to stimulate open thought. The same 'perspective' can have various CATWOE elements. A situation could happen in a CATWOE where the 'customer' can be defined as either the 'service consumers' or as 'funders' by the 'owner'. In Stage 3, a 'perspective' may end up with a very different CATWOE; various root definitions and ultimately a different model.

This form of analysis suggested by Checkland clarifies what the researcher is trying to achieve. By explicitly acknowledging these perspectives, the researcher is forced to consider the impact of any proposed changes on the people involved.

### **Stage 4 – Building the Conceptual Model**

Stage 4 is a study of root definitions by drawing on the relevant conceptual models. Conceptual models are the minimum set of verbs (or action concepts) necessary to describe the effects of the human activity system. Such concepts are seeded in a relevant system and grown in the root definition. The verbs are ordered systemically, articulating the loops that describe the interactions of the human activity system.

Conceptual models are the results of systemic thinking about the real world. The ways in which they manifest in the actual world is addressed in Stage 5 where the conceptual models are compared to the problem situation expressed in Stage 2. Debate can be generated wherein the worldviews inherent in conceptual models are thoroughly questioned and their implications understood. The conceptual model is also employed to identify possible proposals for change.

Each of the verbs in the 'conceptual model' (CM) of the system refers to an activity. Verbs identify how the system 'communicates' and 'controls' its behaviour. A system without feedback can still continue even when the activities which it was set up to perform are no longer required. Therefore, a 'conceptual model' is a description of how a system communicates its elements and controls its performance.

## **Stage 5 – Comparison of Rich Picture and Conceptual Model**

Stage 5 focusses on the comparison with the problem situation expressed in Stage 2. In this stage, the analyst relocates back to the real world from the systems thinking world. The analyst can then compare the conceptual model from Stage 4 with the rich picture of Stage 2. The implications of the comparison to the real world situation can then be discussed.

Debate is generated whereby worldviews inherent in conceptual models are thoroughly questioned, and their implications understood. That may provoke one or more iterations of Stages 2, Stage 3 and Stage 4. For example, real world elements might be missing from Stage 2 or the ‘relevant system’ chosen at Stage 3 was less relevant than the analyst thought or the people in the ‘real world’. The results of the first cycle can help determine if and how the problem situation has changed.

The conceptual model is also employed to ascertain possible proposals for change. After several iterations of comparison with the conceptual model developed at Stage 4, the ‘real world’ situation outlined at stage 2 will be close enough to move into justifying Stage 6. This comparison will frequently lead to suggestions for real-world improvements based on the reasoning of the conceptual model.

## **Stage 6 – Systemically desirable and feasible**

Stage 6 is used to develop desirable and feasible interventions. The process firstly challenges the value of the human activity system and captures it in the systems model after which the value is discussed. Secondly, the issue of utility is explored in the context of the problem situation. The attitudes and political interactions are explained. In this Stage, in order to gain the leverage point, the methodology manages to stop being sequential and starts turning back and forth through all seven stages of the method. On the basis of this analysis, possible interventions are explored.

### Measures of Performance

When specifying the CATWOE attributes, it can be useful to establish criteria by which the system performance is measured. Three fundamental principles are helpful in every situation:

**Efficacy ( $E_1$ )** - indicates whether the transformation provides the intended outcome

**Efficiency ( $E_2$ )** - indicates whether the least possible amount of resources is being used to implement the transformation

**Effectiveness ( $E_3$ )** - indicates whether the transformation helps to realise a more long-term goal (i.e. if it fits into a long-term strategy of the system)

Experienced SSM practitioners might point out that the procedure of the seven stage model is rather rigid. Nevertheless, two positive aspects can be discerned. Firstly, there is flexibility in using the SSM methods outlined above as a toolbox from which appropriate means can be selected for tackling a broad range of organisational tasks. Secondly, there is the emergence of a second, parallel stream of analysis described below as 'cultural enquiry.' It is at present less well developed but in general there are three modes of review:

**Analysis 1** - analysis of the intervention, which clarifies the person who commissioned the study (roles of client), problem solver(s), and the problem owner(s).

**Analysis 2** - 'social system' analysis, which explores the culture of the situation. It focusses on the social position of people in the problem situation (role), the expected behaviours of the people in the problem situation (norms) and the beliefs about the merit of those behaviours of roles of the holders (values).

**Analysis 3** - 'political system' analysis, which examines power and how it is expressed and exercised in the problem situation.

## **Stage 7 – Action to Improve the Situation**

Stage 7 seeks to explore reasonable adjustment between the contrasting opinions and interests that are examined as part of the process of SSM. In this stage, there must be clear understanding of the action taken to implement the changes agreed at Stage 6. The implementation of agreed upon change proposals gives rise to another problem situation. This is where the methodology comes full cycle, and potentially starts a new cycle.

## **ETHICAL CONSIDERATIONS**

This project required Curtin University HREC Level B ethics clearance as it involves incidental personal knowledge about individuals with Down syndrome. All research participants were provided with an information sheet describing the research and explaining that they could withdraw from the study at any time without penalty. All contact data for participants was kept separate from the research evidence. The use of pseudonyms and numerical codes has been used to remove personal identification from the collected data. The study has obtained accreditation in professional and government institutions in Malaysia.

## **FACILITIES AND RESOURCES**

The facilities and resources required to conduct the study included:

1. All essential facilities as described in the Curtin “Essential facilities for PhD students” document
2. Audio recorder
3. Access to a licence for the complete Adobe collection
4. Funding for travel (from the PhD student consumables budget)
5. Funding monies for conference submission and attendance

## **DATA STORAGE**

Data files and the thesis are to be stored electronically on computer with two backups. The supervisor will hold one backup. Only the researcher and supervisor

will have admittance to the files, and a password may require. All records will be kept for a period of 5 years and securely destroyed thereafter in accordance with Curtin University policy.

## **SUMMARY**

This study used Mixed Purposeful Sampling that collect data that began with Qualitative analysis. Mixed Purposeful Sampling included snowball and purposeful random sampling. The process employed the combination of purposeful random sampling and a snowball sampling strategy (Huberman & Miles, 2002) in establishing setting and grouping. This had achieved the recruitment of the sampled 29 participants in the study adapting mixed purposeful sampling attempting to link the multiple interests and needs of participants in the Malaysian care system. The reason for purposeful random sampling is to manage a study's sample size and to offer the researcher a way of discovering information through non-systematic ways, decreasing the influence of the researcher in framing information (Onwuegbuzie and Leech, 2007).

The concern of limitation in adopting two different research models is not adopting probability sampling techniques. A sampling technique that gives all sample collected in its process gives all the participants in the equal population changes of being selected. This may significantly limit the researcher ability to make a broader generalisation from the research result. In turn limits the study's ability to qualify itself as a grounded study.



## CHAPTER 4

### Analysis of Data

#### 4.1 OVERVIEW

Drawing from the ‘voices’ of participants has brought forward the key internal relationships within disability support services in Malaysia and intermittently linked these to the broader external circumstances. Hence, this chapter contains two parts. Firstly, data were analysed through the objectives of the dissertation. Secondly, data were analysed through each research issue and then organised systematically using visual diagrams (including the visual representation of organisational systems of disability support in Malaysia). The study revealed that arts-based activities, as well as physical activities that focus on motor skills when introduced into other areas of education for PDS, can maintain the students’ interest in learning and help students to be creative, take productive action, and have fun while learning (Viglione, 2009). When special education is combined with art education, it challenges students to learn in a creative environment enabling them to gain a deeper understanding of the world around them (Baldacchino, 2012; Chessin & Zander, 2006; Hick & Thomas, 2008). Although the researcher examines the role of education in the arts, the arts themselves cannot be extracted from the wider issues of system complexity that have revealed themselves in the research. SSM is a model that test the data collected from Design Thinking model.

The SSM on the other hand, will display the data that is organised and systematically using visual diagrams (including the visual representation of organisational systems of disability support in Malaysia). While separately visual diagram from Qualitative Analysis where illustrated because it is designed through Design Thinking model [P]rototype. Both visual diagrams illustrated with Design Thinking model and SSM will display two distinctly different methods of diagrams because of differences research model.

Malaysia is a nation with diverse cultural, social, and religious beliefs and a network of ideas, ideology and social practices. It became apparent that it was

necessary to separate art education activities out from the second section in the SSM analysis where it could be misrepresented within the wider contexts in which the diagram was situated. From this point in the analysis, in-depth focus on art education was replaced with a broader review of the disability case problem that reveals the interrelationships of stakeholder concerns. However, without the initial research into arts education, it is important to emphasise this broader network of visual diagram would not have revealed itself. The logical consequence of revealing this data through visual diagrams would be a final and subsequent stage of targeting this information to specific demographics. While this is a logical consequence it is however beyond the scope of this project, but the last study briefly discusses the speculative future of the project where unstructured diagrams would need to be turned into specifically targeted structural diagram.

## **4.2 INTRODUCTION**

The aim of this chapter is to contextualise the development of social inclusion for people with Down syndrome within Malaysia's socio-political organisation and workforces, engaged in disability support in Malaysia. The research analyses the complexity of disability support services in Malaysia in an attempt to understand better the integrated planning of these services. Stakeholders of this research should be able to extract information more easily from the construction of visual representations than from the network of ideas that are currently available from multiple sources such as word of mouth, the internet, and communication other forms of representation. The visual diagrams are the objective, edited record of the aspects of the disability support services, organisational structure and relationships revealed by the research.

Data collection revealed that stakeholders' decision-making and understanding was limited by the complex, highly interlinked yet segregated arrangement of Malaysian disability institutions and their interrelationships and yet an understanding of Malaysian disability support services as a system is required. Qualitative data from stakeholders' case problems framed key issues for moving forward into a caring society; improving disability support services for inclusive

education, managing disability support and addressing the issues of inclusive education.

The first section of this chapter illustrates the case. It focuses on document analysis on the managing body for disability support in Malaysia that began in 1946. It was in this year that welfare support began to develop the public and the private organisations that support people with disability. The second section addresses, through qualitative analysis, the issues surrounding persons with Down syndrome and their access to inclusive education. This includes the concerns of parents and support services labour force (drawn from interviews and surveys) about deviations from the key principle of care support ideology. Drawing on the intensive literature review, interviews and questionnaire sources, covers the SSM that populate the visual diagrams. This analytical process supports the visualisation of the existing case problem from a diagrammatic perspective and connecting the present to the past in anticipation of the future (Senge, 1990).

### **4.3 ILLUSTRATING THE CASE**

This section has two parts. The first part is a document analysis and the second part is a review of qualitative data drawn from mixed purposeful sampling.

#### **4.3.1 Document Analysis**

Document analysis was determined from both purposeful and snowball sampling. The backgrounds to four institutions that provided services to PDS were reviewed. These institutions were viewed holistically under the Malaysia disability support services; an overview was designed to help frame discussions with participants. Two government institutions and two private institutions that had provided significant programmes to support social inclusion of PDS in Malaysia were selected for examination. All are located in the Kuala Lumpur region, the country's most urbanised region and are among the pioneer disability support services in Malaysia.

Document analysis largely contributed to part one of the study's first objective; (a) To identify an approach that can best demonstrate the characteristics of systems designed to reduce exclusion in the education of people with Down syndrome.

### **Participants' settings and Participants groups (also listed in Chapter 3).**

This research study conducted semi-structured interviews that included 29 participants from the groups listed in Table 1. Interview data were collected between January and December, 2011. Interviews were conducted in Malay and English. All interviews were tape recorded, and verbatim responses to semi-structured questions were translated and transcribed by the researcher, using a standardized transcription protocol. The setting and group of participants were categorised in Table 2 below.

**Table 1: Participant Setting**

<b>Malaysia</b>
<ul style="list-style-type: none"><li>• Taman Sinar Harapan, Cheras (TSH)</li><li>• Pemulihan Dalam Komuniti, KL (PDK)</li><li>• Persatuan Sindrom Down Malaysia, Ampang (PSDM)</li><li>• Kiwanis Down syndrome Foundation, Subang (KDSF)</li><li>• Cheshire Home, Gombak</li><li>• Independent Families</li></ul>

**Table 2: Participant Groups**

<b>Participant Groups</b>
<ul style="list-style-type: none"><li>• Teachers</li><li>• Carers</li><li>• Parents</li><li>• Social workers</li><li>• Service Providers</li><li>• Volunteers</li><li>• Medical Professionals</li></ul>

Data in the field were largely drawn from institutions' material as listed below in Table 5. Institutions that are widely supported by government funding and department of social welfare procedure and policy support are categorised as public institutions. This includes PDK, Lembah Pantai and TSH, Cheras. KDSF, Petaling Jaya and PSDM, Ampang are categorised as private institutions because these institutions are self-funded, supported by volunteering support groups of parents, family members or a stakeholder, and gain less government funding. Colour coded diagram would address participant settings in TSH, PDK, PSDM and KDSF below.

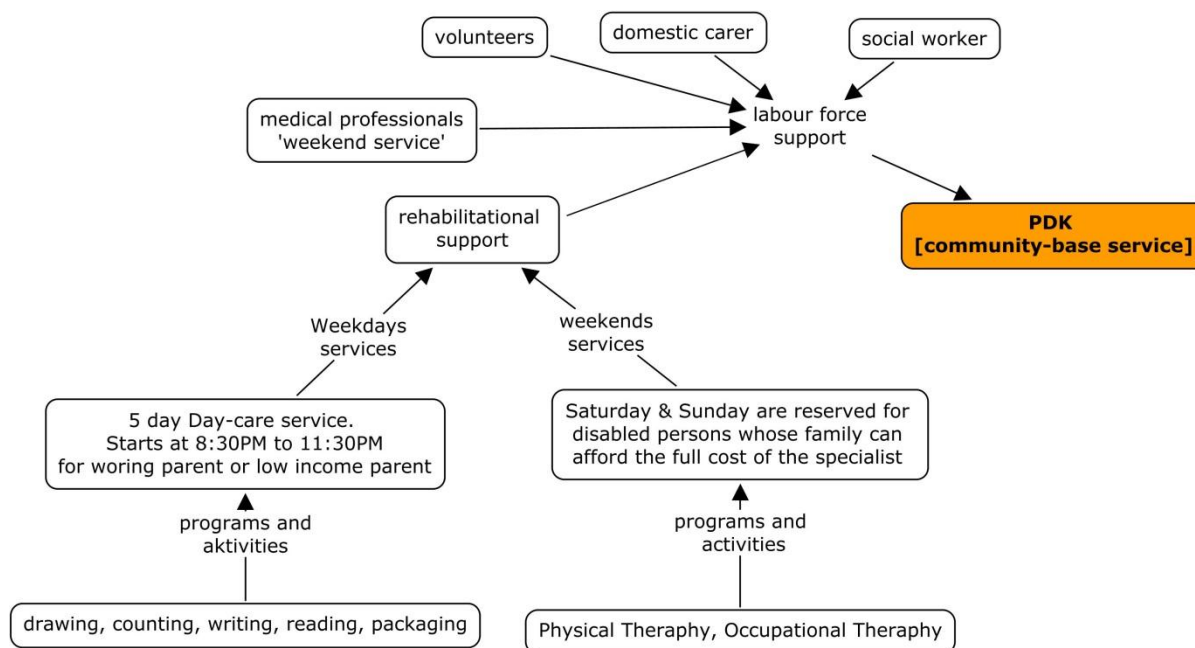
**Table 5: Participant Material**

Document Selected	Data Analysed
PDK	Institutions background, vision and mission, their network support
TSH	Institutions background, vision and mission, their network support
KDSF	Institutions background, vision and mission, their network support
PSDM	Institutions background, vision and mission, their network support

The diagrams below are colour coded to differentiate and identify institutions and their activities. The colour assignation for the institution will be standardised for use in the SSM 7 stage model, stage 2 rich picture, systems thinking procedure.

## Persatuan Dalam Komuniti (PDK)

Diagram 1: Public Institution PDK



### PDK

This study categorised Persatuan Dalam Komuniti (PDK) as a public initiative institution as PDK is an institution derived from the Community Base Rehabilitation (CBR) concept. The Department of Social Welfare of Malaysia under the consultancy of the World Health Organisation (WHO) was directly involved in the initial preparation of a support manual and to evaluate and modify the implementation of its programme (Kebajikan Masyarakat Malaysia, 2011).

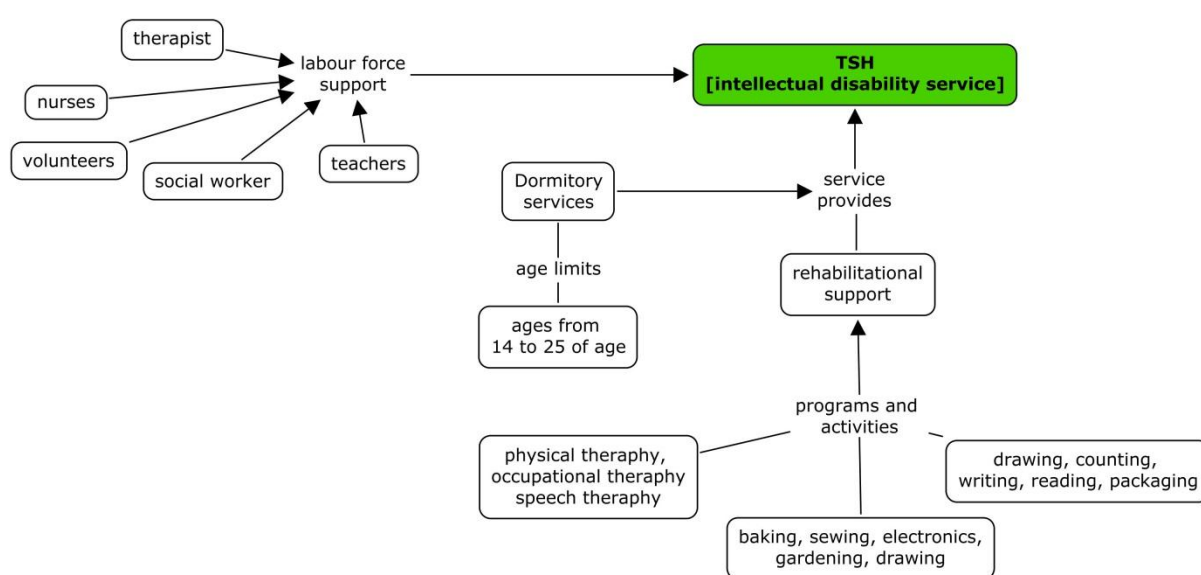
PDK was first introduced in 1983 in Kuala Terengganu when 275 disabled people were identified. The department of social welfare took the initiative to collaborate with the Ministry of Health Malaysia (MOH) to introduce a Pilot Project in 1984 in PDK Mukim Stone Raft, Kuala Terengganu with the involvement of 55 persons with disabilities including people with Down syndrome (Kebajikan Masyarakat Malaysia, 2011).

Since the Pilot project, the PDK programme grew rapidly and the Department of Social Welfare had expanded the PDK programme into every district in Malaysia by the end of 1995. Today many PDK programmes conduct daily activity routines

such as cleaning up, eating, combing hair and toilet training. PDK had also implemented pre-school activities involving counting skills, simple reading, and the basic writing of alphabets and words. PDK also caters the social development of the individual by encouraging participation through introduction of names, age and residence.

## **Taman Sinar Harapan (TSH)**

**Diagram 2: Public Institution TSH**



## **TSH**

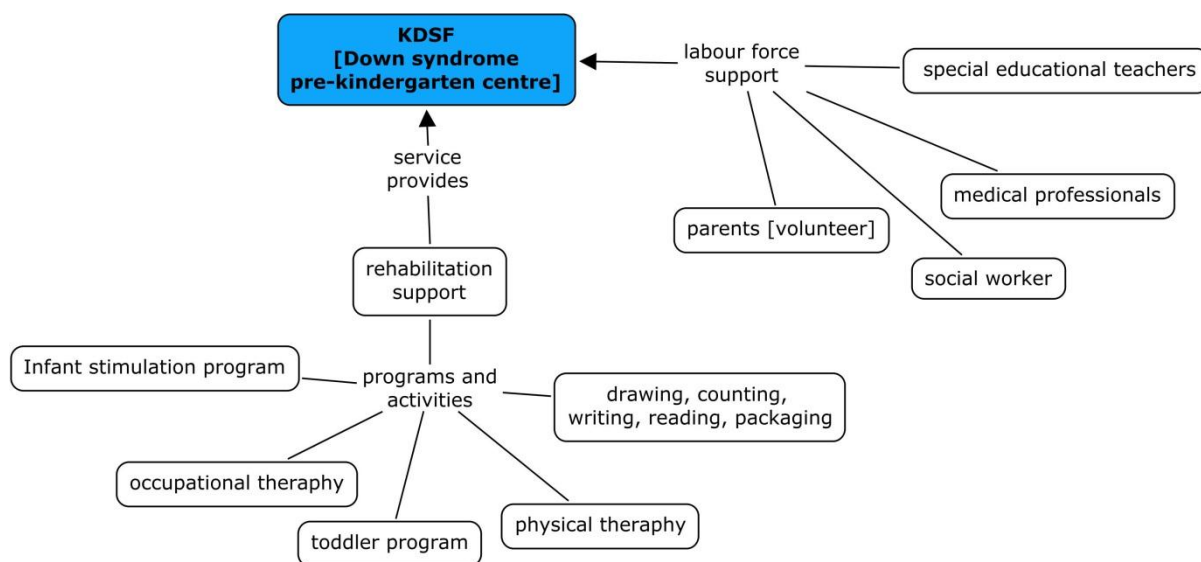
This study has categorised Taman Sinar Harapn (or Garden of Hope) as a public initiative institution because TSH was established in 1947 by the Ministry of Social Welfare Malaysia. It was previously known as the State Children's Home, with the mission to provide protection and care to children who were abandoned, orphaned or had no guardian (Department of Social Welfare, 2011). In 1978 the institution objectives developed to provide care and training programmes to children with disability.

The institution was first named *Akal Sejajar*, then it was changed to Taman Sinar Harapan Tuanku Ampuan Najihah in honouring the name of His Highness, General Ampuan Negeri Sembilan (Department of Social Welfare, 2011). The institution had provided care to all categories of children with disability, either moderate or severe condition; however in 1984 the institution limited the acceptance to children with disabilities under the age of 14 who are educable. The children of the accepted from the children institutionally accepted for care suffer from diseases such as cerebral palsy, Down's syndrome, hydrocephalus, speech and hearing impairments.

TSH provides shelter to 100 children of various races. Activities programme include preparing mentally handicapped children for daily living and adulthood, providing basic education and skills that is suitable to individual needs, and assisting parents and other family member to improve their standard of living while reducing the burden of caring for their child with intellectually disability.

### **Kiwanis Down syndrome Foundation (KDSF)**

**Diagram 3: Private Institution KDSF**



### **KDSF**

Kiwanis Down syndrome Foundation (KDSF) is characterised as a private institution because it is a fully private institution support by Kiwanis Club Kuala

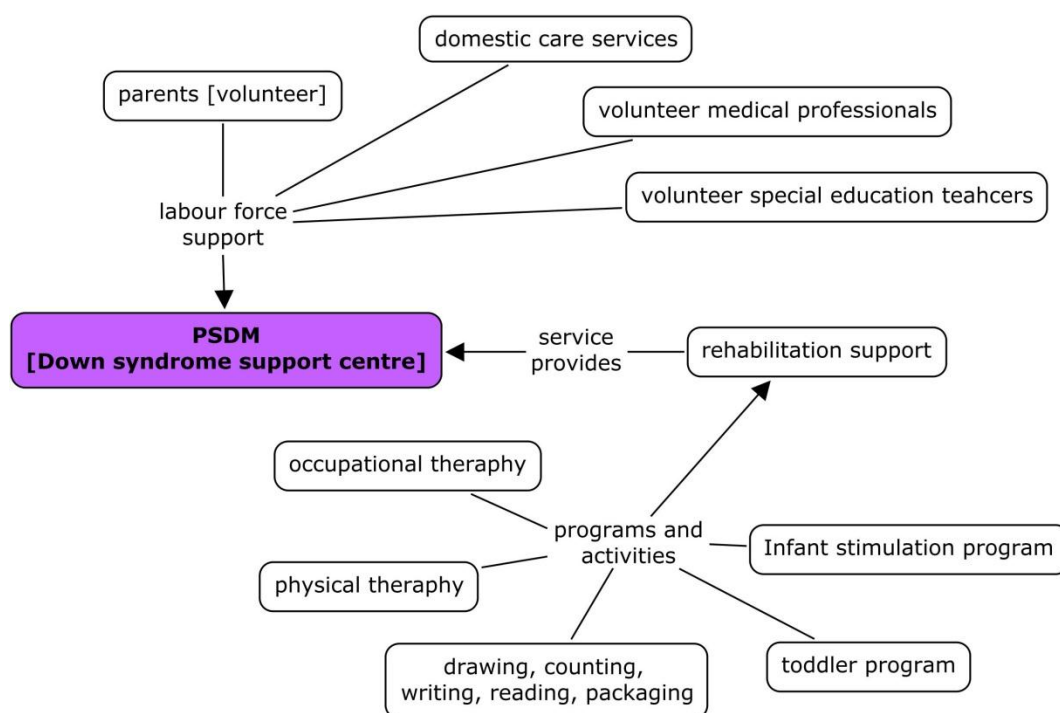


Lumpur (Kiwaniis Down syndrome Foundation, 2011). KDSF's first class was in 1989 with 2 teachers and 15 children with Down syndrome. Currently with a new building, the school had much improvement with new premises designed with a specialised environment for PDS learning and play sessions. The new KDSF is able to accommodate a much larger resource & toy library, a physiotherapy and occupational therapy room, a speech therapy room, 2 wading pools and a multipurpose hall.

The programmes available in the KDSF include the Infant Stimulation Programme, the Toddler Programme and the Special Education Programme. These activities and programmes are included for parents and volunteers (Kiwaniis Down syndrome Foundation, 2011). Enrolments continue to grow and KDSF now has more than 130 children and employs up to 20 teaching staff and therapists (Kiwaniis Down syndrome Foundation, 2011).

## **Persatuan Sindrom Down's Malaysia (PSDM)**

**Diagram 4: Private institution PSDM**



## **PSDM**

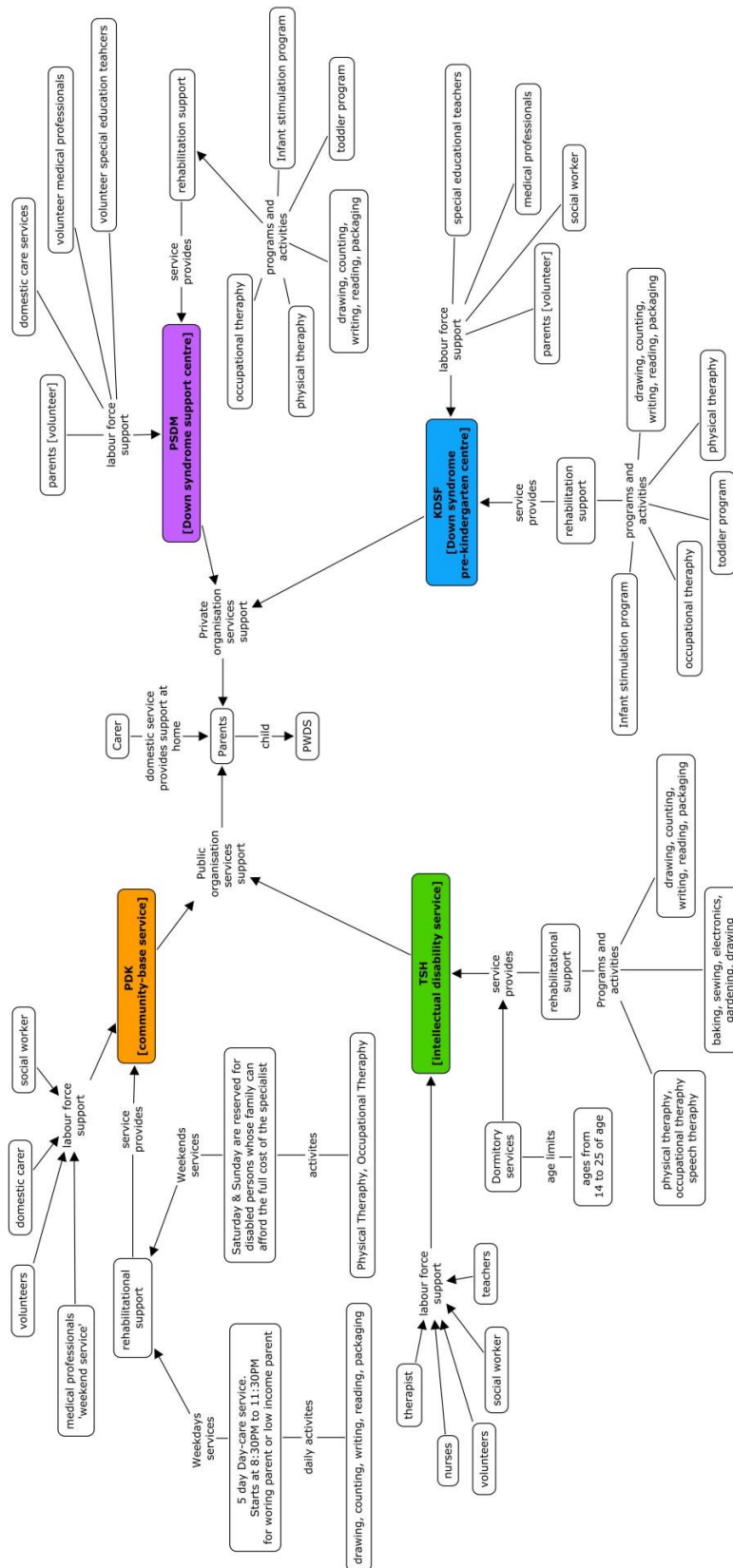
*Persatuan Sindrom Down's Malaysia (PSDM)* is characterised as a private institution because the PSDM started as a parent support group. PSDM began to notice the importance of volunteerism for an institution. The institution was formed in 2001 when the first parent support group registered under the aegis of the Registrar of Societies on May 11, 2001; the sole intention is for parents of children with Down syndrome to have a better future for their children (Persatuan Sindrom Down Malaysia, 2011).

PSDM gained their recognition from the Department of Social Welfare. PSDM achievements are admirable in looking after the welfare of individuals with Down syndrome and their families. These achievements were made possible with support and help from the Ministry of Women, Family and Community Development (MWFC), Ministry of Health (MOH), Ministry of Education (MOE) and various Corporations. PSDM works in smart partnership with these three Ministries and various Corporations in order to realise their vision. Being the national organisation responsible for the welfare of individuals with Down syndrome and their families, PSDM currently has eight state based associations affiliated with it. PSDM hopes to look after the welfare of the majority of the estimated 50,000 individuals with Down syndrome in Malaysia.

Below is Diagram 5 which summarises publicly supported institutions K and TSH and privately supported services KDSF and PSDM. The structure of these diagrams has labelled parents at the centre of the visual diagram, indicating the flexibility of their choice. The choice of the parent is to send their child with PDS into a public or private. Alternatively, high income parents also have the choice to hire a domestic carer that can provide care for their child at home.

Diagram 5: Public and private support for PWD

(Large resolution in Appendix A pp. 218)

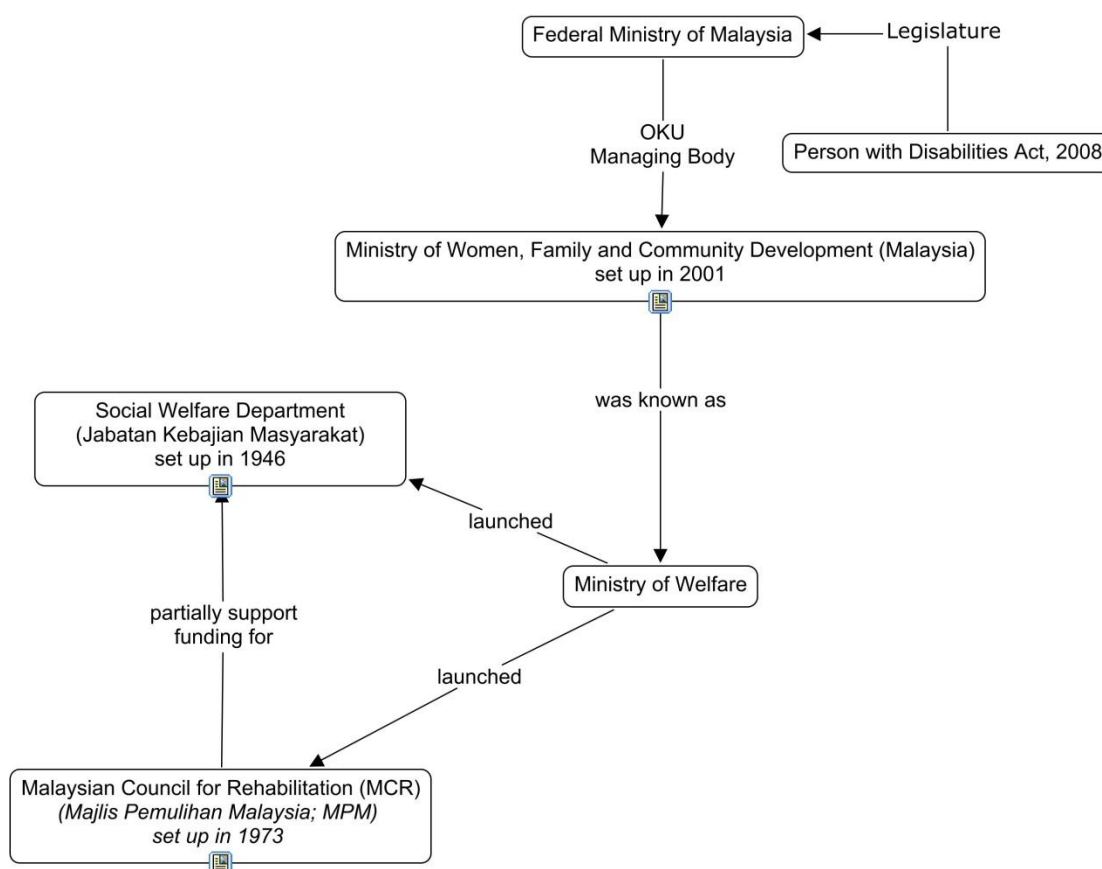


## A holistic view Malaysia's disability support services

An overview of the disability support services in Malaysia follows collected from purposeful and snowball sampling. It summarises the positions of public and private PDS institutions in an all-inclusive view of Malaysia's disability support services.

### Managing body support service

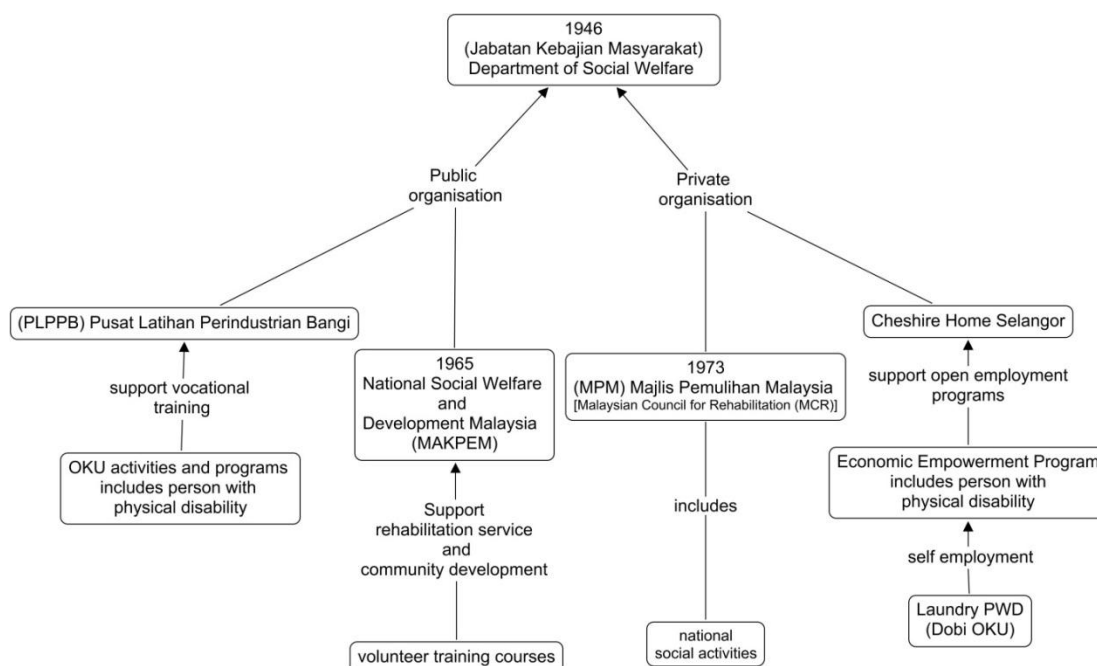
**Diagram 6: Top Management in Disability service in Malaysia**



The initial managing body for disability support services was known as the Ministry of Welfare. It introduced the Social Welfare Department in 1946. In 1973 the Ministry of Welfare launched a private organisation known as the Malaysian Council for Rehabilitation (MCR). Later, in 2001 the Ministry of Women, Family and Community Development (MWFCDD) was introduced and became the first female managing body for the disability movement in Malaysia. This led to the success of the first People with Disability Act in 2008.

## Social welfare support service

**Diagram 7: Social Welfare support Service**



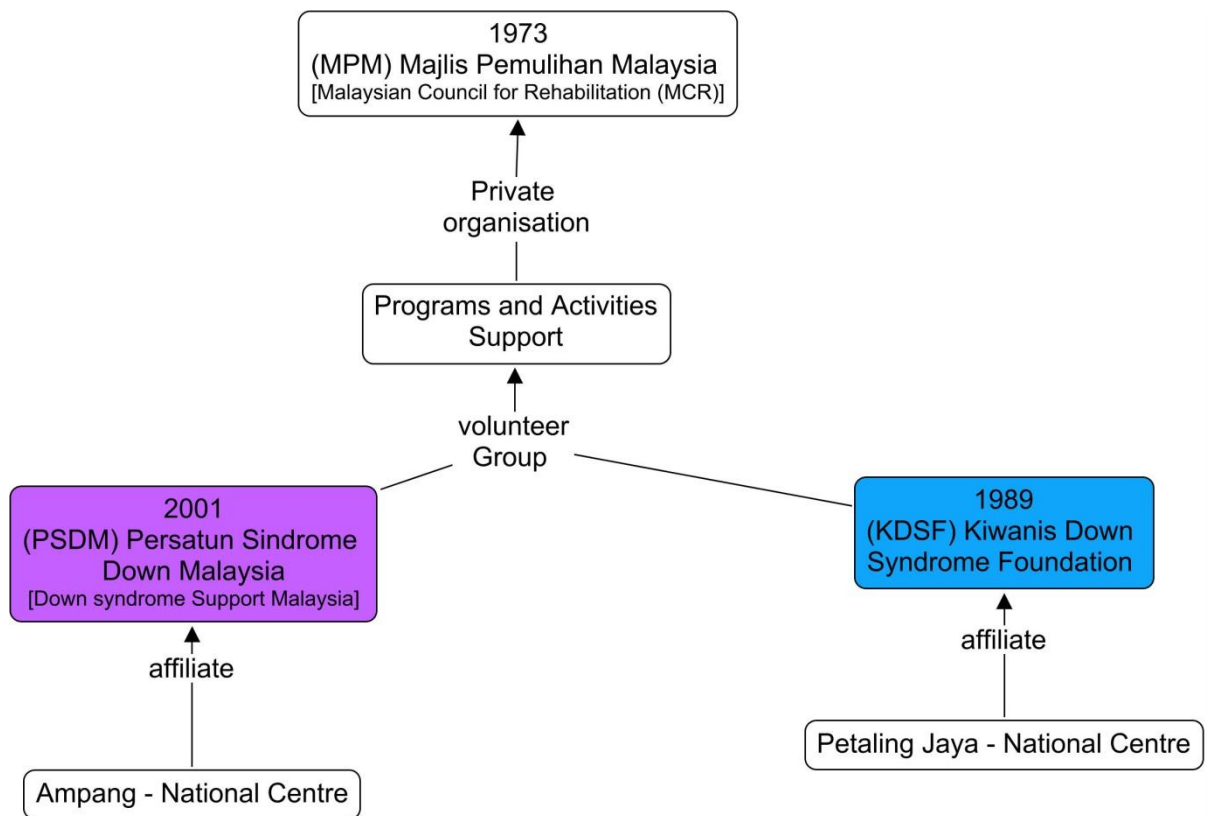
The birth of public and private support service of disability welfare in Malaysia started with the development of Department of Social Welfare Services in 1946. The National Social Welfare and Development Malaysia (*MAKPEM*) organisation was introduced in 1965. This organisation supported local and national rehabilitation institutions and the bonding of institutional community care development networks in urban and rural areas.

In 1973, the Malaysian Council for Rehabilitation (MCR) connected local and national organisations that promoted social learning programmes and activities at an international level. In 1963 a Cheshire Home was established in the Selangor region. Affiliated to the Cheshire Homes East Asia and Pacific Regional council, the home supported vocational training and open employment, and its programmes include an economic empowerment programme which accepts persons with physical disabilities. Previously the PLPP (Bangi Industrial Training and Rehabilitation Centre for the Disabled) institution of vocational training hosted activities and

programmes for persons with physical disabilities; it showed a promising future for OKU in Malaysia.

### Disability support for national social activities

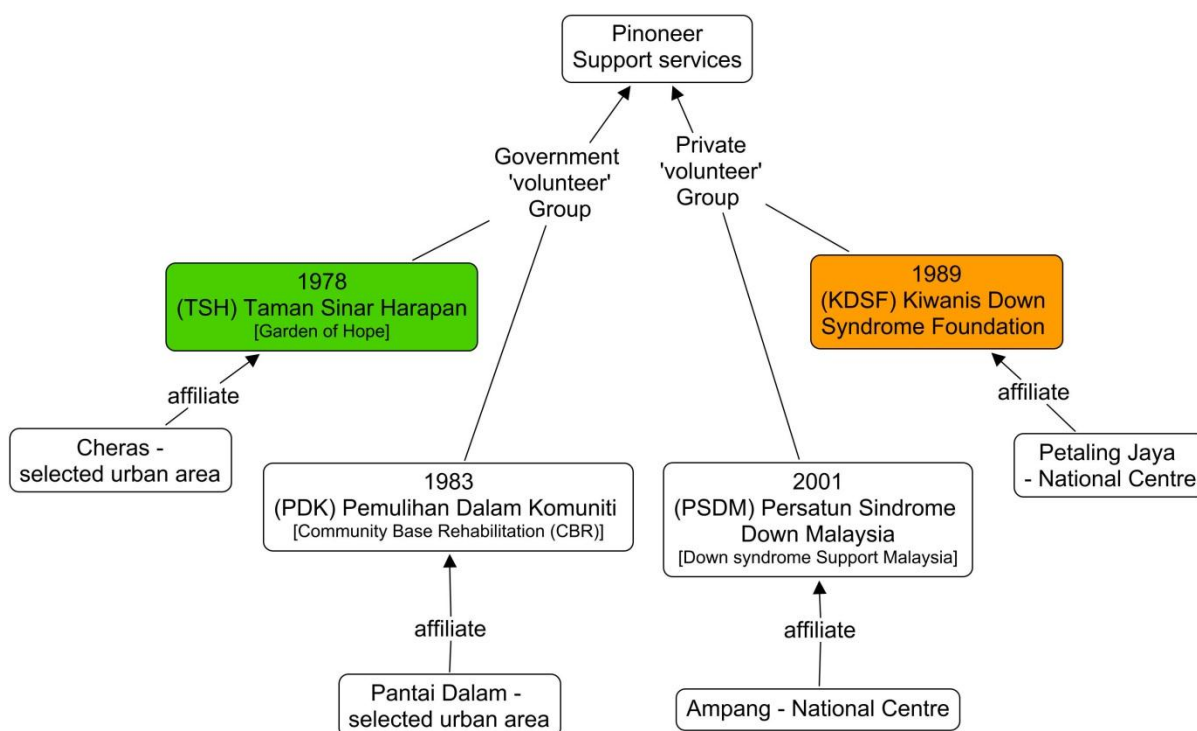
**Diagram 8: Disability support National Activities**



The diagram above identifies the initial, significant private organisations that joined the national social activities pioneer support services organised by Malaysian Council for Rehabilitation (MCR). KDSF today are managing seven Down syndrome Centres across Malaysia including Petaling Jaya, Johore Bahru, Klang, Seremban, Melaka, Kota Kinabalu and Kulai. They are currently pioneering the implementation of the *Early intervention program* and the *Special needs education program* from Robert Dellar's curriculum (Kiwanis Down syndrome Foundation, 2011). PSDM is growing in support services and activities and are managing their institution in the states of Pulau Pinang, Sarawak, Kedah, Perlis, Terengaggu, Melaka, Johor, and Negri Sembilan. They are also implementing educational programmes and outdoor activities programmes for families with children.

## The hierarchy of Malaysia's Pioneer PDS support service

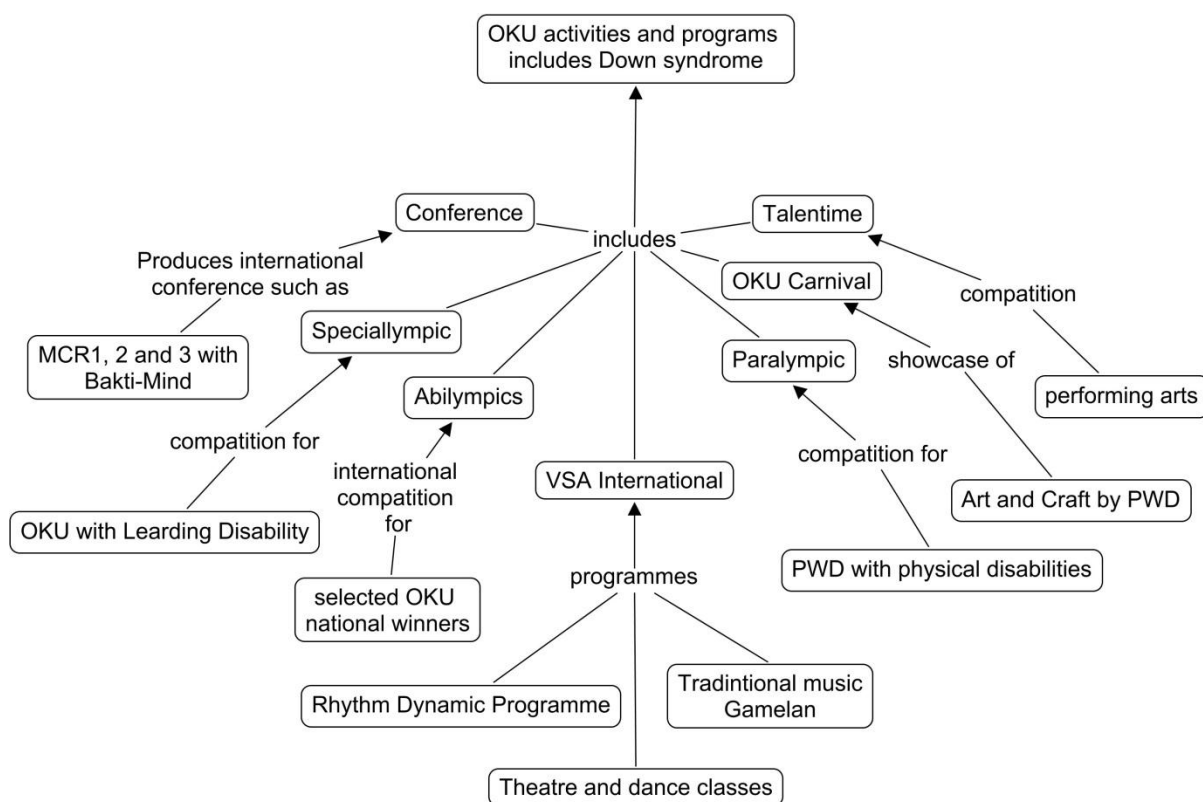
**Diagram 9: PDS Pioneer Support Service**



The above diagram shows the chronology of public and private support service development. TSH was founded in 1978. Today TSH support services have spread into other parts of Selangor, Seremban, Johor, Kuala Terengganu and Kedah. While the first PDK was introduced in Kuala Terengganu, today PDK support services are spread across Malaysia, including states in West Malaysia Perlis, Kelantan, Kedah, Penang, Perak, Selangor, Pahang, Kuala Lumpur, Negeri Sembilan, Melaka, Johor and states in East Malaysia Sabah, Labuan and Sarawak.

## Disability activities and programmes at Local, National, and International level

Diagram 10: OKU Activities and Programmes



The diagram above displays the activities and programmes that support and connect Orang Kurang Upaya (OKU) and their stakeholders. These local activities and programmes also include international conferences and special Olympic sports programmes for OKU with intellectual disability.

Very Special Arts (VSA) International is an organisation that was founded in 1974 and originally called the National Committee – Arts for the Handicapped, becoming VSA in 2010. VSA merged with the Kennedy Center’s Office on Accessibility which made VSA into a Department of VSA and Accessibility at the John F. Kennedy Centre for the Performing Arts. National activities in Malaysia include *Rhythm Dynamic Programme*, *Traditional music Gamelan*, theatre and dance classes and many more. The activities from public organisation include *Talentine*, a performing arts competition for people with intellectual disabilities and *OKU Carnival* an annual OKU arts and craft event.





The above Diagram is a holistic view of Malaysian disability support services, displaying the relationship between public and private institutional support services for PDS in Malaysia.

#### **4.3.2 Qualitative analysis**

Qualitative analysis largely contributed to Objective 1 of the study; to understand the existing design and system thinking approaches for improving skills for people with Down syndrome. The following section reveals the narratives of the semi-structured interview. The information was theme rich. Many of the themes are positioned within the participant's personal experiences of discriminatory situations. A full understanding of the revealed narratives is necessary before they can be visualised in diagrammatic form.

#### **Theme 1**

A discussion of art making is placed first, because the concept of art as a medium to develop problem-solving skills for PDS is a useful route to develop the social inclusion of PDS in Malaysia. Identifying the characteristics of existing potential approaches can help reduce exclusion in education of PDS.

Across the range of parents, stakeholders, social workers, and teachers, all agreed that learning art does help in the early development of the brain. Some participants felt that an art-based programme, while useful, is not the prime method that can assist memory development.

**Participant 9** began with a statement, 'I think art is very important for my son's brain development.' She added, 'My son is working at a hotel, his job is filling shower gel liquids, the job is repetitive and he likes working there.'

**Participant 4** had agreed with **Participant 9** that art can improve brain

development, 'I think people who are involved with arts have more intellect, such as people who learn how to play music are more confident.'

Another parent with a child with PDS experiences visual learning through drawing and understanding pictures of her favourite movie. **Participant 12** had commented, 'My daughter loves arts. Not just arts in drawing. But what I mean is she loves dancing and singing. When we put on music, she would dance and sing with the lyrics. She seems happier when the music that she likes is played. She can read an image and tell you what the story about the image. For example, the image of her favourite cartoon was *Beauty and the Beast*. When she sees the image, she will say right away it is *Beauty and the Beast*.'

A Medical professional suggested that PDS can do art, and it can boost confidence when implemented properly. **Participant 4** had stated, 'Of course people with Down syndrome can do art. There is a definition about this that intelligent people are more creative. I feel that many intellectual people, when involved in art-based programme than they can be, are more intellectual. Their IQ is higher, and their literature can be more in-depth. If a person becomes involved in arts and music, their IQ will be higher. Their critical thinking is higher if a child below four the parent's starts to teach them music, I feel that the child can gain confidence.'

While a stakeholder had claimed that PDS understand repetitive instructions and they do not like drawing, but they prefer performing arts, including singing and dancing. **Participant 8** had stated, 'I had learned that people with Down syndrome are very loving though they appear to be slow at everything they do. They seem to like performing arts more than drawing. They can follow instructions but are forgetful most of the time; what is important is they have fun doing it. It takes time but they will remember the steps.'

A social worker claimed that there is a possibility for PDS students involved in selling their painting because this is a way to support the institution and for

the community to notice PDS. **Participant 1** had suggested that the art made by PDS could sell. The money collected could support as funding to the institution, 'There is a person with Down syndrome here in PDK that draws colourful chickens, and the way the chicken drawn is consistent. We like to take the students artwork and frame that can become a sellable product...and this way the community could notice more of people with Down syndrome artwork.'

Another stakeholder had suggested that people with intellectual disabilities can do art, and wants to join forces with together with an academic body to form a cultural centre for people with disabilities. **Participant 5** had claimed that, 'I am going to work with academics in University Malaya to visualise all the varieties of art being done (drawn or painted) by people with disability, this plan will be organised by Malaysian Council for Rehabilitation (MCR). PDS also can be talented in music, in dancing, in art and paintings. This programme plans to include all disabled people throughout the country - physical and intellectual disabilities.'

In 2010 a social art-based activity called 'Talentine' was organised by the public body, PDK. The event involves selling art and craft product made by OKU from PDK and a chance to take part in the Prime Minister's Cup. These activities involve art-based competitions, which also include singing, dance choreography, performing arts.

**Participant 1** provides an explanation; '[t]here is also the programme we're involved with for PDS with learning difficulties, such as Talentine, and the activity programme has a state competition. It involves performing arts, arts and crafts, singing and dancing competition. This activity is mostly for the person with learning difficulties. There are students with Down syndrome involved in the event.'

**Participant 5** had stated, '[t]alentine is from MCR organization project. We have it under a variety of special arts. That means Talentine activities involved

in performing arts and dancing. So we are open to all NGO (Non-government organisation) to participate as an organiser or partner. We do it at the annual affair. So the last activity, we held a big event at Times Square. The Kiwanis children participated; all the NGO student singing. But this is the activities we have to showcase. The Ministry is going to do a very big one; this Project aimed to due at the end of this year of 2012. It is not Talentime; they call it Festival of Arts. We had our first meeting. MCR have been invited to sit with members of the Festival. It is the type of activities and programmes we did many years ago.'

The experience of social workers involved in Talentime event was that the programme was a success because it created an inclusive situation; private and public OKU institutions socialised, expanded their network and it was also a good outdoor activity. **Participant 11** said, 'I have five years' experience here in KDSF. I see the teachers work with the kids and review the assessments. I am too involved in outside activities with other institutions that support people with disabilities, such as MCR. An example of outside activities is Talentime, Special Olympics and the Arts and Craft Carnival, etc. I think these outside activities are inclusive our children with DS because the children at KDSF will meet more people other than our compound; out into the community.'

However, a medical professional who experienced buying an OKU artwork at a national OKU carnival had felt unsatisfied because the works displayed were expensive and did not have much quality. **Participant 4** stated, 'Malaysia has organised a National Arts and Craft Carnival that sells art products by persons with a disability but the artwork that they displayed was too expensive, and yet it has no quality – people at the carnival do not want to buy it.' **Participant 4** argued, 'Why not create something that is of quality, provide a professional art teacher from school and collaborate with the institution. Ask the art teacher to teach students with Down syndrome how to draw and do craft. Rather providing more burdens onto the PDK staff because the staffs have five weeks training to become a volunteer carer and they are not as creative in arts.'

Nobody will benefit when the issue of selling under-quality art and craft product continues.’

A special education teacher also felt that the future for emancipating PDS was not through selling artwork but in theatre training. The shared experiences suggested that selling artwork might not be the best social inclusion programme for PDS. Nonetheless, theatre training has shown much inclusive social interaction among PDS students.

**Participant 10** suggested that art can be a medium for a problem-solving learning and claimed, ‘Problem solving skills can be everywhere. It can be in a painting activity in an art class learning environment. There is also a problem-solving skill there in art-based programme. For example, if you spill a bottle of paint. Let’s say you want the colour red, and you accidentally put yellow in it – this has become a problem-solving situation. What are you going to do with it? In some situation, we can teach our student with DS. We can tell them; ‘Hey, we can do this’ or tell them to make something else out of it. For us, problem-solving skills are everywhere. Spill water on the table – what are you going to do with it? Take a cloth and wipe it off with it. You can do anything with problem-solving skills. Probably an art can be a medium, for problem-solving learning and, like acting, when they have a project they have to work together; it can be the problem-solving’

A special education teacher explained that there are few PDS venturing into painting but, however, there are some PDS youth involved in theatre training. **Participant 10**, discussing theatre training as part of an arts-based programme for people with Down syndrome revealed, ‘In my experience, adult people with Down syndrome do not do much of art-based activities.’

**Participants 4** continued explaining how to use art-based materials to teach the younger PDS age group, ‘[f]or younger age groups we do a lot of arts because our children have a lot of sensory issues and we want them to be exposed to different kinds of materials. So, over here we do a lot of art-based

activities, and we encourage our children with DS a lot to develop skill, but whether it is going to be carried out when they grew older in primary, secondary and adult age I'm not sure. I'm going to a primary school, tomorrow, and I will ask the teacher whether they have a lot of art-based activities or not.'

The attempts to emancipate PDS through art-based employment was recommended, however, **Participant 10** shared experiences that claimed, 'Adult PDS going into employment as an artist not so much, but the youth people with Down syndrome are venturing into drama and there is one group that does art, dancing and theatre performing. I was hoping this can be something that can be used in a career. Maybe in theatre training programme that does art and craft activities that can involve PDS in making props as part of the package in theatre training programme.'

Suggestions were made that a theatre training programme was not just about performing arts, it involves music and drawing as well. **Participant 10** said, 'The creative art and craft piece that involved in the theatre programme can be used as a costume and as props on the stage. For example, if you wants to perform a piece of a story, let's say Cinderella, they can create the programme to make pieces of art and craft theme about Cinderella. With those pieces of art and craft, they will use as props for their performance or promotion items.'

Institutions supporting disability services are aware that there are music programmes available and that such programmes can prepare individuals for theatre training but nonetheless experts in music programme schools are often not willing to take part. The difficulties persist in emancipating PDS students through music when some music schools refuses to teach music due to their other imitations. **Participant 10** shared a situation, 'I want to register my children from KDSF because some of my children, they are very good. They said no, this project is for those who have a music foundation. I said they don't have a foundation, and they are very young – I ask them how they can get a foundation, we are special needs. She said go to other schools that support PDS

(i.e.: Magic Institution). How do I go about it in the future because I can see they are very vocal and really into dancing? I want a place; why can't they accept them? But parents that came back to me said the centre only provides classes for typical normal children, and they do not accept special kids. I felt that they don't have the expertise and secondly they don't know how to teach special kids. So they don't want to teach them. So, in Malaysia has very minimum option on programmes to teach PDS art.'

**Participant 10** explained about the Jumping Jelly Beans Theatre training for OKU, 'This theatre training is from a company called Jumping Jelly Beans. I saw them in the paper, and they provide a class for typical children and I gave them a call. Because some of the children here, they are very good in the theatre. They like to dance and like imitating; they are good with visuals.'

A lot is dependent upon the efforts of individual teachers to implement problem-solving skills either which are either art-based or literacy programmes. A major step is to emancipate parents how to educate their child. **Participant 10** had claimed that, 'That's why I said problem-solving skills are anywhere. Depends on the teachers, how we want to do it, and you need to teach it, including parents. Eventually, parents require the skills to teach problem-solving skills to their child with PDS because the major part is to educate the parents. I quite like the idea of having an employment programme in 'arts' because we don't have a lot or we don't have choices. The choice is only factory work.'

Parents don't know where to place their children as institutions that are not art based are unlikely to accept a PDS child. The cycle is perpetuating, without experience of special needs students institutions cannot develop programmes. **Participant 5** developed this point, 'Consistency is needed in all institution specialising in teaching OKU student with PDS special needs. I think PDS would express themselves better in painting from arts-based programmes. Institutions such as KDSF, Dyslexia, PSDM, PDK and others can take part in national OKU event. That is because the art-based programme has a venue,



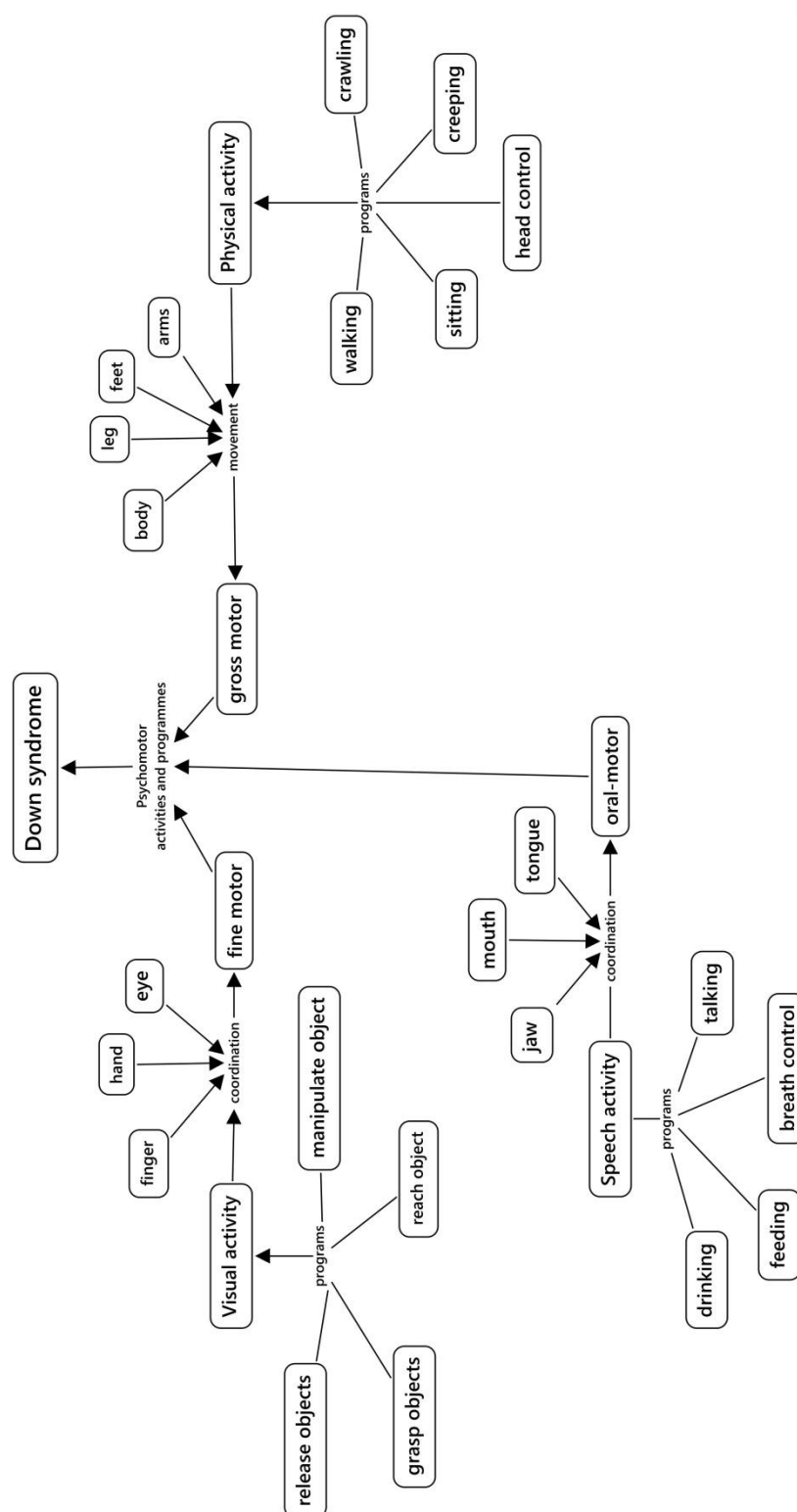
such as working with Art Major experts that can provide skills for PDS students.'

**Participant 10** gave her experiences as examples, 'I think the school don't want to try to teach special needs student. I won't say everybody refuses to teach, but a lot of parents to PDS child had claimed they don't know where to go. A Parent had tried registering their PDS child in a ballet school, but the school would reply stating 'we don't know how to teach OKU'. The moment the term special needs or OKU, professionals in a school would become worried.' **Participant 10** continued, 'Schools had had excuses to time limitation upon teaching of OKU person. Probably the art-based school were scared unless dedicated their time to teaching PDS should not be an issue.'

**Participant 5** said, 'Individuals with physical and intellectual disabilities can do visual arts because art is everything. People with Down syndrome also can be talented in music, in dancing and arts-paintings. They can have a painter work with them, and they can take part in a fashion show, which is one of our projects. I am going to include all Down syndrome stakeholders because the venue is there, so I am going to work with students who are in arts. I have done my part; now it is up to the teachers to educate PDS to educate them to take part in art-based activity because education is the best logical therapy.'

The diagrams that follow map out an objective understanding of psychomotor activities for a logical therapy for PDS (collected in Dmitriev (1982) *Time to Begin: Early Education for Children with Down syndrome*). These can be read as confirming the aspirations of the stakeholders narratives above.

Diagram 12: Recommended Psychomotor activities and programmes for PDS



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graph TD
    DS[Down syndrome] --> R[Read]
    DS --> T[Talk]
    DS --> W[Words]
    R --> VSR[vocabulary skill required]
    T --> VSR
    W --> VSR
    VSR --> M3[3 month - 6 years]
    M3 --> C[cruical level]
    C --> M0[0-3 Month]
    M0 --> RSD[require to develop]
    RSD --> MS[Motor Skills]
    MS --> FSG[Family Support Group]
    M3 --> P[Primary level]
    P --> E7[7 years - 10 years]
    E7 --> S[Secondary level]
    S --> M11[11 years to 17 years]
    M11 --> YAL[Young Adult level]
    YAL --> M18[18 years and Above]
    M18 --> LTM[long term maintenance]
    LTM --> DL[Daily Living]
    LTM --> C[Communication]
    LTM --> S[Socialisation]
    LTM --> RE[Regular Exercise]
    M11 --> RA[require to have rehearsal strategy]
    RA --> TA[Teacher Aide]
    RA --> MS[Memory Skills]
    RA --> RE1[Regular Exercise]
    RA --> SA[Study Aide]
    M11 --> WA[Working Ahead]
    WA --> EA[Education Assessment]
    EA --> RS[strategy required]
    RS --> RE2[Regular Exercise]
  
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The flowchart illustrates the progression of Down syndrome from birth to adulthood, showing key milestones, educational levels, and support needs. The progression starts with 'Down syndrome' leading to 'Read', 'Talk', and 'Words'. 'Read' leads to 'vocabulary skill required', which leads to '3 month - 6 years'. '3 month - 6 years' leads to 'cruical level', which leads to '0-3 Month'. '0-3 Month' leads to 'require to develop', which leads to 'Motor Skills', which leads to 'Family Support Group'. '3 month - 6 years' leads to 'Primary level', which leads to '7 years - 10 years'. '7 years - 10 years' leads to 'Secondary level', which leads to '11 years to 17 years'. '11 years to 17 years' leads to 'Young Adult level', which leads to '18 years and Above'. '18 years and Above' leads to 'long term maintenance', which leads to 'Daily Living', 'Communication', 'Socialisation', and 'Regular Exercise'. '11 years to 17 years' leads to 'require to have rehearsal strategy', which leads to 'Teacher Aide', 'Memory Skills', 'Regular Exercise', and 'Study Aide'. '11 years to 17 years' leads to 'Working Ahead', which leads to 'Education Assessment', which leads to 'strategy required', which leads to 'Regular Exercise'.

### **Summary, perspective no .1**

Participants were concerned at the lack of full understanding in term of social and political needs in the network support system. The lack of understanding hinders the full emancipation of PDS within the community.

All participants gave their feedback on art-based activities and emancipating PDS special needs. Some agreed that selling artwork can allow PDS to be socially independent. Other participants felt that making art can improve PDS brain development. There was a parent that had observed that their child understanding drawing and pictures was a form of visual learning. A social worker felt that selling PDS artwork can generate funding for their institution, as a result of selling PDS art and craft in a festival. PDS artwork can also be sold at events such as Talentime, which were organised and funded by public agencies.

An organised national event such as Talentime has shown an important step in the improvement of social inclusion for PDS in Malaysia. It even provides programmes of friendly competition for OKU with intellectual disability. Programmes includes singing, performing arts and dance choreography. Private and public institutions that involved in this event, felt that the teacher plays an important role in teaching special education OKU students with PDS special needs and also has the knowledge to emancipate parents and their child with PDS into social activities. However, other participants felt that greater network support is needed, and it is important to promote the event even more vigorously. A participant suggested that, without developing network support, emancipating PDS into the community cannot be possible.

### **Theme 2**

Across the spectrum of the participants (carers, parents, stakeholders, teachers and medical professionals) the view is that parental support is important to the long term development of PDS. Participant parents observed that their children will lose their enthusiasm for learning when their child reaches seven years, an experience shared by special education teachers. A carer's personal point of view was that that

there are two types of parents of children with DS. One will advocate emancipating their child; the other continues to hide their child from society.

**Participant 1** felt that there were two types of parents within the Down syndrome support system, best described as parents who enable their child's development through support for activities and participation, and those parents who further disable their child by not advocating inclusion. **Participant 2** further described these two sets of parents when she continued with the following statement: 'Some parents have neglected their child, and they are afraid for their child's wellbeing. I am not sure if they want to support their child or take advantage of the support centre because some parents feel that whatever the centre does is wrong. **Participant 1** continued the argument with a question for the parents: 'Have the parents thought about what they have done to support their child at home?'

However, medical professionals contested the view that the parent is alone in needing needs to be responsible for the child's future wellbeing. The institution should also take part taking part in providing access to information about the available support and even provide transportation.

There were conflicting opinions on the subject of parent support. **Participant 4** disagreed with **Participants 1** and **Participant 2** on the matter of parents neglect. **Participant 4** explicitly stated, 'I think CBR (PDK Lembah Pantai) carers and volunteer's give the wrong impression saying parents are misusing their institution, because CBR (PDK Lembah Pantai) should be more aggressive and set new goals. They have to be more persuasive with the parents in regards to supporting their child. **Participant 4** continued, 'Parents do not know where to go, and they do not have greater knowledge on how to educate a child with Down syndrome. There is no access to information and transportation for the parents and their child to seek assistance.'

**Participant 3** (Manager, PDK Lembah Pantai) felt that PDK as institution is lacking the funds, because of insufficient government funding to hire

professionals to conduct extra activities with the students within their CBR organisations. The participant said that, 'our institution will get a grant from the government worth RM140k annually. This grant is used to pay the staff and bills annually. I feel it is not enough to hire professionals to do activities with the students.'

Furthermore, state funding would be reduced when their PDK institution gets private sponsorship. **Participant 3** explained, 'We get sponsorship from Selangor Turf Club (or Dewan Kuda from Bandar Tun Razak). It is an equestrian charity programme called Riding for Disabled (RDA). We can bring in 4 OKU to the stables to do physical therapy, but that is strictly only for those with physical disabilities. They do not provide programmes for students with intellectual disabilities such as Down syndrome. We also get Starbucks sponsorship for to foster child plan (*Program Anak Angkat*), and Starbucks provides coffee and charity services for us. When we gain support from the two private organisations, our grant from the government was then reduced.'

There are weekend activities involving medical professionals conducting programmes for children in PDK Lembah Pantai, but it is dependent on the parent's capacity to fund the activities of their child. **Participant 4**, however, disagreed with **Participant 3** '... we do have programmes for our students...it is up to the capability of each parent. Some parents can afford to pay extra for the activities of their child...and gain the benefits of doing activities with the professionals...the weekend activities we run with the professionals have their assessment methods.'

Medical professionals actively felt that parents are not to blame for issues of exclusion. The institution is in the position to improve their services modelled on other success stories from different PDK in various states of Malaysia, and PDK is an important place for parents with lower incomes..

Rather than positioning parents as pivotal to the development of their children's social access, **Participant 4** argued that PDK Lembah Pantai is, in

fact, in a central position of power. The institutions have access to a range of vital resources and information that can support a parent in their domestic role. **Participant 4** suggested that PDK Lembah Pantai could play a much larger role in providing information and support to parents, to ensure successful long-term development and social inclusion. **Participant 4** stated that, '[c]arers and volunteers have to educate the parents on how to care and seek support for a child with Down syndrome. CBR (PDK Lembah Pantai) as an institution have the support and the knowledge provided by the Government.'

**Participant 4** contested the argument made by **Participants 1, 2 and 3**, emphasising the parents' lack of knowledge about disability in general is central to causing problems of socialisation. **Participant 4** had stated, '... the support structure was not implemented well at home; the reason for this is that the parents lack information provided by the institution to proceed with a module at home.' **Participant 4** provided a case example, a boy with a learning disability who had enrolled in a public school. '... let us look back on an OKU with learning disability, he was in an intellectual slow learners programme at a mainstream school. When students reach secondary level, they will have to go through the education system and sit for national exams such as UPSR, PMR and SPM to participate in acceptance into the next level of education. Each student, including PDS who are categorised as having a Learning Disability is required to pass the national exams. The boy was supposed to sit for PMR national exams. However, he was not allowed to sit for the exam because the school board may fear that their overall achievement level would drop. In another case, when the boy was not performing according to the school's performance standard, he cannot enrol in the next level of education in the mainstream school. Therefore, the school may choose to send the boy back to PDK (in this case any PDK nearest to the boy's home). This situation happens because the parents do not know what to do and when to take over, in terms of educating their child with a disability.'

Parents are at a disadvantage when a public school rejects a child with a disability. **Participant 4** had given an opinion, "... a child should be in school

learning in a higher education level. However, the situations were not allowing them to be in school because of their learning disability. The boy is now in PDK, and PDK teaches him colouring and doing early learning intervention.'

The medical profession's view on the issue of social inclusion of PDS in Malaysia appeared to be that the public underestimates OKU students with PDS special needs. Having a self-sustaining system that emancipates such students is important.

Nonetheless, **Participant 4** had continued with the following statement, 'I observed that PDK is a safe place. It is a place for parents who cannot meet the private school enrolment fee because private organisation fee is expensive. However, the issue arises when PDK is sometimes does not gives priority to the OKU learning disability students' needs. For example, providing them with self-sustaining skills, that is for emancipating them to be independent. In many of the PDK institution programme continues to teach OKU students PDS special needs to write ABC even if they diagnosed with minor learning disability.'

**Participant 4** shared a view '[b]ased on my experience working with people in the disability sector. I disagree with many people who say that students with a disability do not want to focus because it is not the student with a disability that does not want to focus; it is the programme guideline that can frustrate their behaviour, hence they do not want to focus. Furthermore, many people suggested that OKU attention span is lesser and shorter, and they are very sensitive. Due to this, medically they lose focus very fast. However, my personal view is we are the ones who are not being sensitive to them.'

**Participant 4**, giving suggestions for improvements, continued with the following statement: 'For instance, a system needs to be created. Such as after six years in PDK, the student needs to graduate from the centre and be able to go into employment, such as doing packaging or into hospitality.'



A view from a homemaker parent (**Participant 9**, a housewife and mother to a 20-year-old son with Down syndrome) claimed that being unemployed gives her the ability to care for her child personally and to teach her child to read and write. She shared her story stating, ‘My job requires me to be at home, to make sure my child gets the care and education support that he needs. My husband and I devote our time to him. We would find ways to make sure he understands how to read and write and speak correctly. When my son was younger at 3 to 4 years old, I used to send him to art classes to do painting. Although he dislikes doing painting today, but he can still express his feelings through painting. I think it is good for his hand muscles development because from there he can then learn how to write.’

**Participant 9** continued, ‘My son is a happy person. Today, he loves working at this hotel doing work like filling shampoo bottles in the bathrooms, although it can be repetitive. I worked hard to get the hotel manager to accept my child to work. Every working day I will send him to work, and he loves working at the hotel, I see that he is more proud to be around people who support and encourage him.’

However, there are also working mothers that have difficulty in caring for their child, needing to find domestic care to support them. **Participant 12**, a mother that works and has a 24-year old child with Down syndrome explains, ‘I am a mother. I hire a domestic carer who looks after my child at home. It was hard in the beginning to trust people to care for a child with Down syndrome while I am busy with my work. However, over the years I have learned to manage my busy schedule. There were awkward moments where I didn’t know how to care for my child, and I did not know where to find help.’

**Participant 12** reflected on her daughter’s condition, ‘She became the backbone of our family and the glue that sticks us together. Nonetheless, I do feel that my child as an adult could be more healthy and independent and could have a social group of friends. My greatest fear is for her future wellbeing if I were to die before her.’

Parents involved with PSDM have a different perspective. They are part of the parent committee and supporting the child's wellbeing and getting the best education for them is their number one priority. **Participant 6**, a mother who had taken an early retirement had shared her side of a story, 'I took an unexpected retirement to care for my child with Down syndrome. I eventually became part of the parent committee in PSDM. I am very pleased of my first two sons; they both work as engineers. My other son is in a famous band called 'Estranged', and I have a daughter who has dyslexia. She can be stubborn, but she likes hands-on work, so I let her study makeup, and my last son has Down syndrome. I was shocked at first maybe because of my age, but I slowly learned to cope with the situation, although my son diagnosed with mild Down syndrome. I took early retirement from my job to make sure I can give him 100% of my attention. I want him and all my children to be fruitful and independent.'

**Participant 6** explained how she gained her role in a parent committee in PSDM, 'At first when I sent my son to PSDM I just wanted to support with care. Making sure of the activities and programmes in PSDM would provide full support for my son. As time passed, I shifted to become an active member in PSDM. I was elected to be on the parent committee. Although, I am a volunteer parent, and I don't get paid for doing this job, I have donated money to PSDM to support children with DS. My mission is to make sure PSDM is run properly while having a strong syllabus; complete with assessment and activities to make sure each child will get their independent treatment. My opinion, other people, can join our organisation and invest to open another PSDM in a different area, just like a business.'

**Participant 7**, a parent housewife, illustrated her role as a mother and volunteer in the parent committee, 'I am a housewife. I also care for my child at home and the centre as a volunteer. I am a parent committee member in PSDM. It is a volunteer role. My task in PSDM is to monitor financial involvement coming in and out of PSDM.' **Participant 7** had indicated that her child with Down syndrome had involved in performing in a theatre, 'My

daughter has mild Down syndrome. She loves to sing and dance. In 2010, we organized a ‘Gala Dinner’ that had risen funding for our institution and my daughter, together with our PSDM kids, performed a drama act as entertainment at the dinner. It was a success. Our staff, parents and extras from the drama department came and joined in for support. My daughter loves to be part of the act because she gets to sing and dance, she played the part of a tree in the musical drama called ‘Living Forest’. I feel that she gained courage because she had to perform in front of a large audience. She is more confident to talk to people, not as shy as she was before. I feel that all the kids who participated in the drama loved being part of the event because they made new friends with the crew from theatre act.’

Nonetheless, being in a parent committee is challenging because they require care services for their child while managing the activities in the institution. The parents and carers worked hard to prepare the children to remember their moves in the musical drama, explained **Participant 7**, ‘Preparing for the event was difficult. We had to practice every 3 to 4 days and sometimes every day to make sure the kids remembered when to move and how to move for the musical drama. It was hard work for all of us including the carers, volunteer trainers and the teachers. However, the joy we get from seeing the kids performed pays off.’

Stakeholder feels programmes that seem to emancipate a child with PDS could, however, unintentionally misuse their role to improve business rather than promote a caring society. **Participant 8** had the claim an overview situation, ‘...in my personal experiences, some parents and companies misused the funding and person with Down syndrome for the sake of promoting their businesses.’

**Participant 8** had continued with an example, ‘The Gala dinner event was to promote the wellness of people with Down syndrome. However, the problem with our Gala Dinner emerged when the Production Manager and a parent in the performing team decided to make a profit to promote their business. But

we had to go on with the production because it was to support the event as a ‘Gala Dinner’. To ensure people with Down syndrome would get enough support financially and emotionally, we needed to have networks that can provide activities and programme that emancipate PSDM kids to be self-sustain.’

Organisational support for children with Down syndrome stops as they get older, and such people can easily become isolated. Thus, interviewees suggested that an Early Intervention Programme (EIP) is an important aspect of institutional support.

‘Parents who have a child with a disability such as Down syndrome will face difficulties’, explained **Participant 1** who continued, ‘... when a person with Down syndrome reaches adulthood, for instance at the age of 16 and above parents become uncertain. To whether to place them in school, or send them back to PDK, or let their child stay at home with a domestic carer, or send to a private institution, or even considering sending their child with a disability to an institution of intellectual illness.’

‘In most cases, an adult with Down syndrome would stay at home’ claimed **Participant OPC1**. That is why an institution such as PSDM requires an OKU student with PDS special needs that reaches adult age will have engage with an EIP. **Participant OPC1** had explained the situation, ‘... the activities that PSDM organises for accepting adults with Down syndrome [starts] when they grew isolated from interaction with people. We would be re-training them using Early Intervention Programme (EIP). We aggressively re-train them with EIP because since they were comfortable being alone at home they will forget to be independent and thus becomes dependent on the parent or carer or family member at home. The reason we use EIP is to train them again in the skills they have forgotten so that they can learn to be self-sustainable in the community.’

Although there are activities organised in public and private institutions, sometimes parents faces trust issues with these support networks, leading the

parents to continue with domestic care support even though many network support systems have organised learning activities and programmes. **Participant OPC1** had expressed her point of view about parents, stating, 'There are many reasons [parents decide to keep their children at home when they reach the isolation stage]. One, maybe the parents do not trust outside or external care. Two, they might be too busy to drive their child to the centre. Three, there may be a situation where parents do not have extra money to pay for the private tuition. Four, maybe, parents just do not know where to go. Whatever the reason might be, when parents decide by themselves for their child with Down syndrome to stay at home, it will result in isolation of their child. That can be very dangerous for a person with Down syndrome because firstly, they will become comfortable with the idea of being isolated at home without social interaction. Secondly, PDS will eventually forget their skills learned at school when they were at a young age such self-sustainable skill set. I think parents should recognise that a child born with Down syndrome will have distinct characteristics that include short attention span and PDS need professional treatment when compared to domestic care support.'

A special education teacher stated that parents do not have to be 100% responsible for their child's wellbeing as institutions include a programme that encourages all parents to participate in certain provided activities. **Participant 10** shared the experience of working with parents with a DS child, 'It will not be the parent's responsibility when the child graduates from kindergarten in KDSF. Our school encourages the parent to participate and help them to reinforce the knowledge they have learned and apply it at home.'

The special education teacher pointed out when attempting to emancipate a child with DS, independent skills are valuable and that PDS require lifelong learning and continuous support, However, parents are less eager to support their child's development when their child reaches a certain age. **Participant 10** observed, 'Parents' enthusiasm may reduce when the child reaches a certain age. For some parents, when the child reaches seven years old, they lose the capacity to cope with their child with Down syndrome dependency. Most

parents would think that when they give EIP at an early age the child will become independent. However, this proves to be a contradictory fact. For instance, sometimes when we teach a person without physical or intellectual disability, they can understand and they can continue on their own to be independent and self-sustaining. However, a person with Down syndrome is different. In my experience, teaching Down syndrome is a lifelong education even at whatever age, for example, at age 7, 16, 24, 36 and older. You (as the parent, carer, teacher, stakeholder, medical professional) will still need to teach and support them continuously. I feel the most important skill is independence skills that unfortunately in Malaysia, we do not focus on independent skill, we are more focused on academic skills with national exams.'

However, teaching skills for independence can be difficult. Some PDS face separation anxiety that need the parent to be present at all times. Some parents with a DS child lack trust in a teacher to educate their child while they are in school. **Participant 10** explains the obstacles that teachers and carers face when a child with Down syndrome cannot separate from their parent, 'We have issues such as separation anxiety. The mother will provide everything for the child, for example bringing them to toilet. This can result in a lot of dependent behaviour. When parents wish to register the child. The child will become scared because of the sudden exposure to large groups. Then they have to adapt to routines such as circle time programme and getting accustomed to doing things on their own, like only taking off their shoes, going to toilet, or using their hands when eating.'

**Participant 10** elaborated on the course at KDSF, 'There are many learning styles that can be used to suit a child with Down syndrome. I think the methods carried out are different for individuals with Down syndrome. Maybe because people with Down syndrome have different biological characteristics, and they have the potential to lose focus quickly. Thus to keep track of their development, KDSF has a progress report for each different child, it requires the teachers to monitor every student's development every day.' **Participant 11**, a social worker working in KDSF, agreed with **Participant 10**, adding,

‘When working with a person with down syndrome, a parent and the trainer needs to be calm. Teachers and parents then can learn patience. Because a child with Down syndrome has a lower IQ and physical function, they can pull a tantrum if things do not go their way.’

The programme in KDSF only supports PDS from baby to 7 years old. **Participant 11** had clarified that KDSF is an organisation that nurtures children in the early intervention programme, ‘We prepare them to get into primary schools but we do not train them for employment. ... We do have older persons with Down syndrome who are today 23 to 30 years of age. We do not keep feedback or progress on their adult activities. We managed to encounter a few of our adult students, but most of the time they stay at home. We only have one PDS working with us. He is good at grammar and English, and he sometimes helps with my English. He has his transport because his parents can drive him to the centre, and they pick him up afterwards. I think he also receives work benefits from the government employment funding.’

The family is central to providing a care system that can help encourage PDS to be socially independent. **Participant 5** discussed how family values play a central role in a person’s wellbeing, ‘Family values are important. It has to start at a young age’ she said, arguing that parents acquire a broader value system that is committed to social inclusion, ‘It must be in you, in your heart. How the families were brought up is important. We need that compassion toward the neighbour, people around us and especially persons with disability.’ **Participant 5** agreed, ‘Again, to me, all success revolves around family, even like my ‘*Dobi Project*’ (Laundry Project). If the family is not cooperative, the children will not be part of the *Dobi Project*.’

**Participant 5** had shared an example from a OKU self-sustainable business, ‘A documentary by TV3 showed an OKU, who goes to work and uses public transportation around him. It is fantastic what TV3 did for the boy by documenting his journey to work. The boy was proud. I think we need to salute this boy an OKU. It was a good observation from TV3. So this is one

example. But, of course, what motivates me and the community more is to continue to support OKU because we can find a lot of things to do for the children. We can give opportunities to them, and we can aid them through funding. Nevertheless, in the end, parents must come in to be the sole supporting mechanism.'

Some medical professionals have claimed that PDS require special medical treatment rather than focusing on their social wellbeing. That requires PDS to be treated in a sheltered environment such as Taman Sinar Harapan (TSH). This institution provides personal attention and specialised therapy for OKU with severe physical and intellectual disability such as PDS.

**Participant INTP15** stated, 'I think Down syndrome is an intellectual problem. Those with Down syndrome need constant medical assistance. Some parents would send their child with Down syndrome to TSH to seek long term care service. TSH is an institution for people with severe intellectual disability. We provide sheltered learning and physical training. Patients who stay here are kept for 1 or 2 years, maximum. At the end of our weekly service programme, the parents should take their child back. In my observation, some parents would leave their child for months before taking them back home. There are other cases where the parent wishes to come every day to bring their child back with them. In some instances, we have nurses who act as teachers because the education department does not have enough special education teachers to come in and educate our students (patients with a disability). We have nurses who pose as a baking teacher and sewing teachers. Our special education teacher focuses on art and academic activities.'

**Participant INTP14** observed, 'In my opinion, I find that people with intellectual disability have the potential to be socially active in the community. As I observed that many people with intellectual disability, such as PDS at an international first world countries, they are doing daily chores and even having their wedding. Another person with Down syndrome is an expert at playing piano and violin. These cases showed that individuals with Down syndrome in



Malaysia do have the potential to be socially active, as compared to the international situations. However, many Malaysians may regard this situation otherwise because of PDS has a weak mental and physical abilities. They are slower at remembering what they have learned in class. They can pull aggressive tantrums when frustrated. I believe Malaysians, including parents, consider that people with Down syndrome are in better and safer conditions when placed in a sheltered environment like TSH.'

### **Summary, perspective no .2**

A common comment about the barriers to social inclusion for PDS in Malaysia is parent blame. A few participants categorised parents as unsupportive because of their lack of participation in the social activities provided by institution. Other participants disagreed claiming that the institution has the power to be more assertive and to provide more support services for their client and their family members and lack of funding should not be an issue.

However, many families do play a role to support of their children with DS in providing support and including them in daily social inclusive activities. Some participants suggested that greater social engagement is the key to providing the development to successful care support and concern towards PDS. The *Dobi Project* in Kuala Lumpur provided an interesting example, in which stakeholders had sponsored the support of a group of young adults with a disability in their laundry business. Participants suggested that parents and family members, carers and teachers are also required to be part of the support system of children with a physical or intellectual disability.

### **Theme 3**

This section of the study examines a series of discussions amongst and about labour forces and their concerns surrounding the barriers to social inclusion for PDS in Malaysia. In this section, dialogue was between educators, social workers, parents, stakeholders and teachers.

Social inequalities in volunteer support were described in two ways. First, having a voluntary job, for example as a ‘carer’. Second, doing volunteering at a managerial level in institutions. This support is an essential requirement in the management of institutions.

Conversations with selected Participants are discussed below:

**Participant 5**, a stakeholder, has been a volunteer for 30 years. She has gained a position in the private sector in the Malaysian Council for Rehabilitation (MCR). She stated her concerns about the social inequalities in the labour force. ‘As a volunteer, I am more worried about the way committee members treat volunteers, rather than having an actual focus on the disabled people, having to take care of our volunteers, or else they will go to a different NGO. I respect all volunteers, but I feel disappointed when people regard themselves as VIP volunteers. It causes discomfort in representing themselves as the primary support for OKU.’

**Participant 5** provided an explanation for the volunteer’s situation in Malaysia, ‘I have spent around 30 years as a volunteer. To become a volunteer means to do jobs in the service support, freely and it is unpaid. 30 years ago, I came to this home (Cheshire Home, Selangor) and helped with fund raising and other activities. Eventually, I went into the committee. The situation in a committee as a top management challenging since, I was the only secretary. So because of my experience, I was very meticulous – this was like being in the hospitality industry. I was able to transform a home into a much more organised state. I did not just commit voluntary work. Voluntary means it's not necessarily a big commitment, in the committees you have more responsibility, and you need to have very structured plans to do the job. Voluntary support is a commitment. It's like running a business. I work as a CEO, but I'm not on the payroll.’

**Participant 8** commented on social inequality, ‘I am not a big fan of carrying out volunteer jobs with the parent committees in PSDM. They call themselves volunteers because they support PSDM by funding. I consider that my role as

a volunteer in PSDM is being mistreated. I think my sole purpose was to make awareness. When I glance at the situation in PSDM, it is more of a business, and they use Down syndrome to gain pity cash. However, this is only based on my opinion.'

There was discussion about misleading volunteers. **Participant 8** provided an example of the process of hiring a volunteer in PSDM, 'Please be aware the example is from my judgement in my personal experiences. The parent committee wanted to organise a Gala dinner for 2011; the idea were to provide chances of PDS getting better treatment and acknowledgement by the society. They decided to call me and a friend to generate ideas for a theme of the event. We did so and presented our idea to the parent committee, and they went ahead with it. In general, I wanted to do the design work for charity purposes. However, the parent committee requested for a quotation. After I have submitted my idea and concept, the parent committee came back to me and said it was too expensive and decided they did not want my service. I was shocked because I had mentioned to them that I yearned to do the project for charity. Therefore, my service is for free. Later, after the Gala Dinner, I found out that they went and used the idea and concept I had suggested to them, unfortunately for me, with a different designer. I felt honoured my ideas was put to good use however it was upsetting that they didn't acknowledge it to me first.'

There were suggestions that social status plays a part in social inequalities. **Participant 8** had commented, 'The volunteers in PSDM are mostly parents who have children with Down syndrome. Based on my personal point of view, I think they mostly came from a highly paid status. As an example, one of the parents in the committee is related to an elitist who is the founder of the Cheshire home. Another parent works as a Doctor in a hospital in Kajang, Selangor. There are many higher status people doing volunteer jobs, some just gave money, while others just simply wanted to be part of the process and some provide funding maybe to promote their name.'

The roles of a parent committee are to provide funds and managerial responsibility. **Participant 6** described her role in a parent committee in PSDM, ‘At first when I sent my son to PSDM. I just wanted to care and make sure the activities and programmes would provide full support for my son. Soon, I became an active member in PSDM, and I was elected to be part of the parent committee. I am a volunteer parent, and I don’t get paid for doing this job, although I have donated money to PSDM.’

**Participant 1** and **Participant 2** in PDK Lembah Pantai Institution had expressed their personal feelings of being overwhelmed by the tasks for their volunteering job. **Participant 1** made the following statement, ‘...we do multitasking job, but not the kids. We get stressed over different types of people with disability (OKU). We have to teach the kids to be skilful. We also have to juggle our schedule to work in becoming carers, teachers and social workers and to divide our time for each individual with OKU and also PDS special needs in our institution.’

Although, disability policy had provided disability rights to education the disability policy assumed that all disability training in a mainstream public school should take place in a separate classroom. OKU students that do not perform well in mainstream public school are transferred back to PDK. In this context, **Participant 4** talked about people with disability in a broader aspect and specifically about people with Down syndrome; ‘[the] ministry office had assumed that people with a disability [would be managed] in mainstream public schools, but they will have a special class for themselves and called that being integrated. Those who ... cannot perform are not accepted in mainstream public schools and recommended registering with CBR (PDK).’

The teacher in TSH explained, ‘I think the disability policy in special education policy in Malaysia is blurry. Meaning education policy and disability policy did not implement inclusion procedure that claimed to care for OKU freedom and justice. We have integrated classroom methods in public schools for people with disabilities. However, we found many students with

disabilities continue their education in public school and do not perform. They are sent back to a segregated centre, such as in TSH or CBR.'

Public schools are required to integrate OKU students with PDS special needs and provide a structured education. **Participant 10**, a special education teacher with ten years' experience teaching in KDSF explained, 'Programmes for public school teachers, such as an inclusive programme, have not yet been implemented for people with Down syndrome. Probably soon, because inclusion is still very new in Malaysia. In fact, it takes time, effort and patience to train individuals with Down syndrome. In my opinion, Malaysia probably needs a well-structured system for teachers to understand what works and what does not for students with Down syndrome in public and private schools.'

**Participant 1** had described the teaching method PDK used to train people with intellectual disability, 'We will have the intellectual disability kids do *'Early Intervention (EIP) Activities*. ... Although, I was born with a handicapped arm. I obtained an opportunity to work for PDK. I got a job in PDK Lembah Pantai and assigned as a volunteer supervisor. But to the OKU students, I am their teacher. The students feel comfortable with me and call me 'Teacher'. The government gave me an opportunity to work and the students like me. Nonetheless, I do not hold a degree in special education or have years of experience. Though, I earned my training from the government programme in National Council of Welfare and Social Development Malaysia (MAKPEM) or *Majlis Kebajikan dan Pembangunan Masyarakat Kebangsaan Malaysia* and other opportunities.'

**Participant 4** disagreed with **Participant 1**, declaring that professional teachers should have many years of training in understanding the methods of health, care and development of an individual with an intellectual disability. 'The positions of teachers who specialise to support people with Down syndrome were substituted by inexperienced educators.'

Years of training are needed to be a special education teacher and years of experience are required to understand PDS behaviour, Participant 4 continued, ‘...What is happening in PDK is that the staffs, including carers, are the ones becoming or acting as teachers after they have received training for only five weeks from MAKPEM. At MAKPEM, the training was about ‘how to care for OKU’ and ‘how to become a carer’ for OKU. The staffs at the PDK do not know how to run the programme simply by going through learning ‘how to improve on OKU motor skills on a basic level’. In my observation, PDK Lembah Pantai should have proposed to the teachers from ‘KEMAS’ the Department of Rural and Regional Development or *Jabatan Kemajuan Masyarakat*. To come into their institution to teach the OKU students with PDK special needs, for example, on ‘how to cook’ or ‘to do vocational work’. Another example, PDK in Melaka has used a different method. They would invite teachers to show ‘how to sew’ and they would have a room for the teachers from ‘KEMAS’ to work with the students with disabilities including students with Down syndrome.’

When OKU students with DS special needs cannot maintain their ability to sustain themselves, unfortunately, they are in a position of disadvantage, and devalued. For example, **Participant 10** explained, ‘Mainstream teachers probably have different expectations when dealing with students with Down syndrome. To us, pupils with Down syndrome who studied in KDSF can colour and draw circles but the teachers in mainstream public school expected that the student with Down syndrome can only scribble and not colour. To us, that scribbling is a form of an achievement for them. The expectations are different in the mainstream public schools. The way I see it, my students with Down syndrome can colour but they are slow, and I cannot compare them to average children. It’s not fair for the child.’

A mother, **Participant 12**, that studied in an international university enrolled in Minneapolis, USA had a child with PDS with her while studying and was upset with Malaysian public institution disability support services. She shared her personal experiences, ‘the school here has six teachers to one OKU student

with PDS individual needs. [In the US] there were physical activities, art and craft sessions and grocery shopping activities. That's what my daughter used to learn in school. There were writing and speech lessons. I remembered my daughter learned to write and pronounced her name. She even learned how to draw faces with eyes, nose, ears and hair. Now, we are back in Malaysia, she unfortunately stays at home because I do not know where to send her. Many public schools do not want to accept her because my daughter is categorised with a low-functioning disability. I also do not want to send her to community care support because I do not trust their services.'

Some families are concerned about specialised education and treatment when PDS students are not able to be accepted in public schools and are too old for private specialised PDS institution, and have no choices other than to enrol in TSH. During an open conversation with a teacher in a TSH public institution for intellectual disability, **Participant OPC1**, a teacher for primary language teaching in Bahasa Malaysia, stated, 'Not many specialised teachers wanted to teach in TSH because I feel that the place is stressful. The students here are very slow, and they have tantrums and health issues that we have to care for additionally. So when the management said that there were not enough teachers to educate people with disability, they were wrong. In my personal view, there are many teachers out there but teaching in an institution for persons with intellectual disability is not popular.'

When a child with Down syndrome has graduated from KDSF and if able, enrolled in a mainstream public kindergarten school, the child may not be treated well by public school teachers. **Participant 10** relayed her experiences, 'So in public kindergarten, teachers would give a long instruction in one sentence to the children and the students with Down syndrome would not understand it. Maybe the choice of words the teacher used was different. Therefore, the child could not understand, and so they could not deliver what the teacher requested – that could be one issue.'

In addition, teachers require patience and new teaching methods. **Participant 11** claimed that, ‘KDSF has a progress report for each different child, and the teachers will monitor every student’s development. Teachers and parents need to have patience. They also require behaviour management to understand how to manage their child with Down syndrome. Because PDS can throw a tantrum if things do not go their way.’ **Participant 10** suggested, ‘When we try to show something new, such as colouring within the lines, it cannot be forced. Either the mainstream or special education teachers must encourage them patiently and consistently to do it. If you insist on strength and hold their hands while you guide them your way with them, to colour within the lines, they will get frustrated.’ **Participants 10** concerns (from a special education teacher perspective) continued; ‘Another issue was the sign language. The child may have understood what the teacher wanted. Let’s say a teacher described A for Apple, and I knew this child who could converse in sign language but not verbally because the child cannot speak. Maybe the teachers in public school (kindergarten level, primary or secondary) did not understand what the child wanted. But for us in KDSF we have been trained to see the child will use sign language back to us, like being in a conversation.’

**Participant 10** continued, ‘Somehow the teacher said the kid kept doing this and that. The teacher could not understand their students with PDS, so they marked the child as incapable of learning but here in KDSF, we do learn the sign language, which became our a great achievement. If teaching methods are not implemented accordingly to PDS behaviour there can be consequences, **Participant 10** observed, ‘you will kill their creativity and kill their interest ... even though they love playing with colours. Anybody can disrupt their focus and make them lose interest just by forcing them to do things without their consent because a person with Down syndrome has characteristics different to that of a person without Down syndrome.’



### **Summary, perspective no .3**

Participants were upset and overwhelmed by the concerns about social status in the care system, and this discussion reinforced the researcher's position on arts-based programmes as being a medium or a tool for learning, rather than the solution to inclusive education. The feedback from the participant's feelings, opinion, experiences shared many concerns about social inequalities and treatment. There were concerns about disability policy and comments were raised as to how to further improved the disability and education system as it translated into the different field of development needs. There are concerns that when PDS students move to public school that teachers do not know how to maintain PDS behaviour. Participants face the burden of multiple tasks in funding and providing support to gain professionals that can train PDS individual needs.

## **4.4 SOFT SYSTEM METHODOLOGY (SSM)**

The third part of this section is a systems thinking analysis within the framework of Soft System Methodology (SSM) (Checkland & Poulter, 2010). SSM procedure contributed to Objective 2 of the study. Document analysis and qualitative analysis provide an overview of concerns about the disability support network in Malaysia. (However, it does not examine the information in terms of design research).

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## Overview of SSM procedure

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Stage 1: Problem Situation Presented below.

Stage 2: Rich Picture Presented below.

Stage 3: Root Definition presented below

- I. Root definition (an analysis procedure) is applied to reveal how a system works (Checkland, P., & Poulter, J., 2010), that comprises element in CATWOE. PQR is a formulation of root definitions was used to start a solid foundation of CATWOE. PQR formula in SSM, do P by Q in order to achieve R. (Checkland, P., & Poulter, J., 2010).

i.e.: A system to do<what,P> by means of <how, Q> in order to (why, P>

- II. Holons (is a transforming process), reveals why a system works the way it does (Checkland, P., & Poulter, J., 2010).

Stage 4: Design conceptual mode of system thinking world 1 in visual diagram.

**B: to evaluate the consequences of design model decisions in a complex situation such as disability issues for PDS in Malaysia (in Stage, Stage 6, and Stage 7)**

Stage 5: Rich Picture and Conceptual Model

Stage 6: Desirable and feasible Intervention

- I. Measures the performance in Root definition. The model used a different CATWOE, different perspective, and different subsystem (theme) that referred to 3 basic criteria recommended by Checkland (Checkland, P., & Poulter, J., 2010). i.e. Efficacy E1, Efficiency E2,

Stage 1 and stage 2 presents REAL WORLD situation in RICH PICTURE.

Stage 3 until stage 7 presents System World situation with comparison of CONCEPTUAL MODEL 1 (CATWOE) and CONCEPTUAL MODEL 2 (BATWOVE)

and Effectiveness E3 and analysis 1

clarifies the role of client Analysis 2, or

- II. Similarly measuring performance can be achieved using BATWOVE, which B as Beneficiaries and V as Victims.
- III. CATWOE vs. BATWOVE
- IV. Description of different CATWOE perspective and subsystem- Perspective 1, 2,3,4,5, and 6

Stage 7: Action to improve situation

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#### **4.4.1 SSM, 7 Stage Model**

The data presented in the previous section explained both through themed narratives and a visual diagram the uncertainty of disability issues in Malaysia. These issues have come to a point of such complexity that there is a need to employ systems thinking processes to rationalise and clarify the situation. The claims arising from the qualitative analysis of data are now to be aligned within SSM. As Tufte remarks, when information is presented from a different perspective, it becomes a tool for assessing the credibility of evidence (Tufte, 1983).

The SSM process firstly collects the data (in this case qualitatively gathered) and analyses it using real world comparisons. Secondly, a conceptual model is formed by comparing the collected data with systems thinking. It is employed to improve and explore possible actions and actions and interventions. Initially real world situations are explained in through visual diagram. Later stages describe from a systems thinking perspective.

### **(Stage 1): Problem situation**

The findings framed through narrative data and a visual diagram suggested issues creating barriers to the social inclusion of PDS in Malaysia. The findings provided significant information that can start a discussion within the SSM, 7 stage model. The question below was constructed using the SSM, Stage 3 PQR formula that begins SSM analysis; (PQR formula in SSM, do P by Q in order to achieve R (Checkland & Poulter, 2010).

How does soft system methodology justify exploring possible interventions in confronting barriers to social inclusion of PDS in Malaysia, compared to comparison to a synthesised simulation of a real world situation represented in the qualitative data?

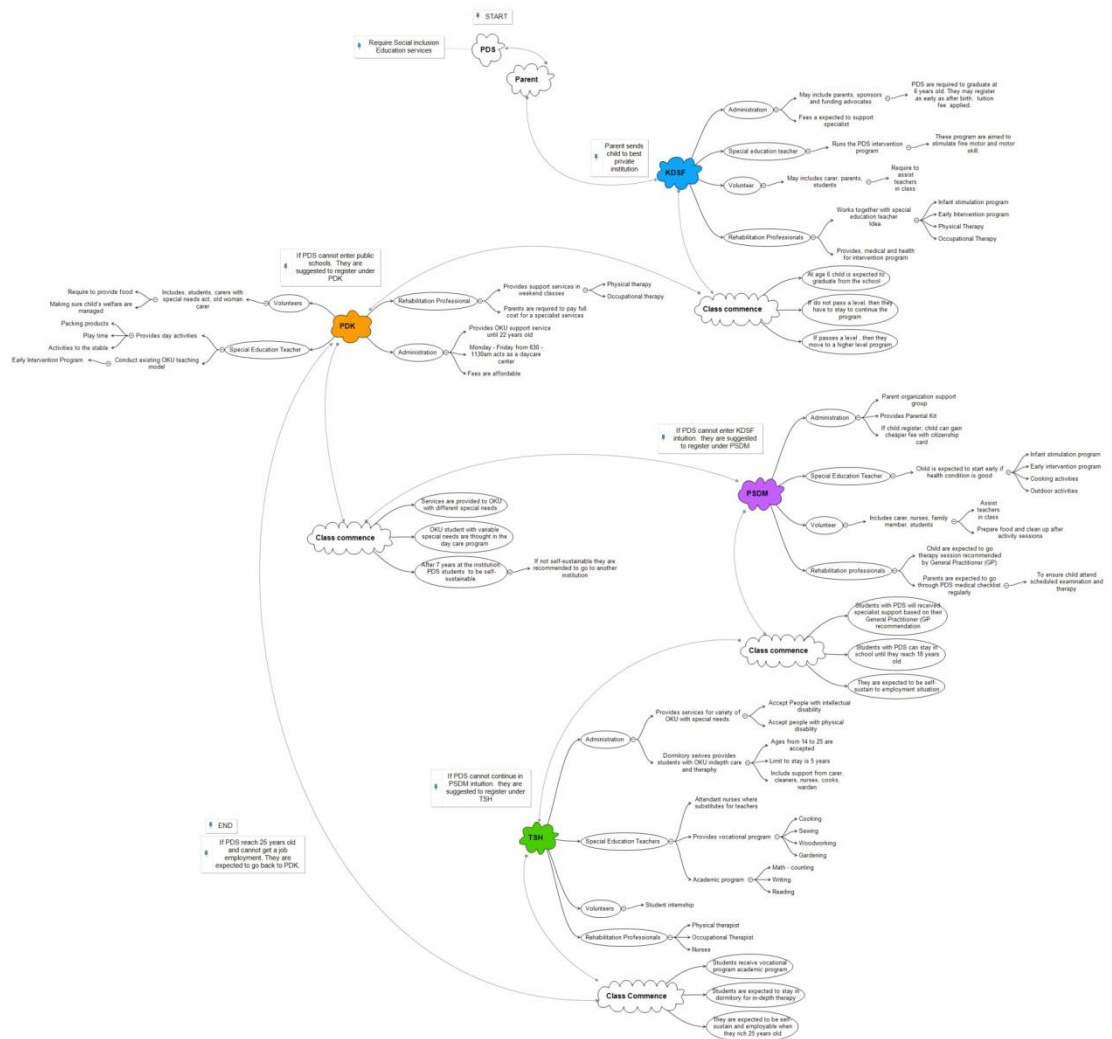
### **(Stage 2): Rich Pictures**

Below are visual diagrams, illustrating disability support services, derived from previous findings in document analysis and qualitative analysis. Diagram 14 describes the 'rich picture' visualising the situation derived from Themes 1, 2 and 3.

To read the diagrams below is from top to bottom.

**Diagram 14: RICH PICTURE Diagram for Theme 1, Theme 2 and Theme 3**

(Large resolution in Appendix A pp. 218)



## KDSF

Begin reading the diagram from the label 'START'. The first variable is labelled 'Require social inclusion education service'. The variable illustrates the problem of a parent sending their child with PDS to KDSF. The illustrated branch on 'KDSF' indicates the network of support that provides the full interventional education programme for PDS. Support includes 'administration'; this group includes parents,

sponsors, and funding advocates. The entry fees are applied to support tuition cost. The policy in KDSF states that every child with PDS is required to graduate at six years of age. Special Education teachers are a group of support team that runs the course for PDS. The courses include an Early Intervention Programme (EIP). Courses such as psychomotor are aimed to stimulate PDS fine motor and motor skills. Volunteers are groups of support that include carers, parents, social workers, and even students. Volunteer are required to assist teachers in class. Rehabilitation professionals are groups of support team that provides medical and health intervention programme. Rehabilitation professionals' work closed with special education teachers to bring suitable intervention plan for PDS such as infant stimulation, early intervention, occupational therapy and more. The next illustrated branch is 'classes commence'. This branch describes some of the consequences the parent and their child with DS would encounter when the child enters KDSF. Every child with DS is required to pass every level of programme regardless of age, and are expected to graduate at six years old.

### ***PDK***

The next variable indicates 'If the child cannot enter public school. They are suggested to register under PDK'. Parents with child PDS are advised by social welfare organisations to place their child under PDK. The PDK illustrated branch indicates the network of support that provides services for people with disability that include 'high' and 'low' functioning disabilities. Network of support includes 'Administration' office that provides the terms and conditions when placing child with a disability. PDK is a support service that has to provide care for anyone with a disability to 22 years old. A 'Special education teacher' is required to provide activities for students in the school. 'Volunteer' includes students, carers, and parents who can register to volunteer their time to support managing food and the child's welfare needs. 'Rehabilitation professional' are available during the weekend, and parents are required to pay fees to attend the specialist service such physical and occupational therapy. The next illustrated branch under PDK is 'classes commence'. This branch demonstrates the consequences that parents and their child with PDS would encounter in PDK. It includes the services provided in PDS for people with a disability and all types of needs, which include physical and intellectual disability.

PDK is an organisation that acts like a day care centre. The time limit for enrolment within the organisation is seven years. Students are expected to be self-sustainable. If the children with disability are not self-sustainable, they are supposed to register with a different organisation.

### ***PSDM***

PSDM is the next illustrated branch. It represents a variable for parents in search of other community support for their child with PDS, 'If PDS cannot enter KDSF institution. Parents and their child with PDS were suggested to register under PSDM'. This illustrated branch indicates the network of support that provides services, and the system of support includes 'Administration'. It consists of parent support groups; the organisation provides a 'parental kit' that helps other parents to care for their child, while for registration for a PDS with Malaysian citizenship is cheaper. A 'Special education teacher' expect students with PDS to be enrolled in the school and to be registered early as infancy if they have good health. Programmes and activities included in the class are infant stimulation, an early intervention programme, cooking activities and outdoor activities. A 'Volunteer' at the school may include carers, nurses, family members, students. They are required to assist teachers in class, prepare food, and clean up after activities and programmes. 'Rehabilitation professionals' at the school request that the child undergo therapy sessions recommended by their general practitioner. Parents are expected to go through the PDS medical checklist regularly which is to ensure that the child with PDS can obtain necessary scheduled examination and therapy sessions. The next illustrated branch is 'classes commence'. This branch demonstrates the consequences that a parent and child would encounter. Students with PDS can stay in the school until they reach 18 years old, and they are expected to be sufficiently self-sustaining to meet employment.

### ***TSH***

The last illustrated branch is TSH. The branch has a variable; 'If PDS cannot continue in PSDM institution. They are suggested to register under TSH'. The network of support includes 'Administration' which consists of rehabilitation professionals, and carers that range from professional nurses, cleaners, nurses, cooks, dormitory wardens etc. TSH has dormitory services for parents that want extra

professional support for their child with a disability. OKU students in TSH will get in-depth care and therapy support. The school will only accept students' ages from 14 to 25 years of age. Stays at the dormitory are limited to five years. 'Special education teachers' in TSH have nurses as substitutes for teaching in the vocational programmes. The nurses teach cooking, sewing, woodworking, and gardening. Academic programmes include maths, writing and reading. The courses held are run by teachers with a special education background. TSH volunteer positions are provided only as internships for students with professional knowledge about rehabilitation. 'Rehabilitation professionals' in TSH includes physical therapists, occupational therapists, and professional nurses the next illustrated branch is 'class commences' which explained the sequences when placing a child in TSH. The intention is that students self-sustaining and they are expected to be employable when they are 25 years old. The students at TSH are required to stay in the dormitory for in-depth therapy, vocational and academic activities with rehabilitation professionals. The TSH branch leads to the next variable 'if PDS reach 25 years old and do not get employment. They are expected to go back to PDS'. The diagram leads back to PDK where the cycle of the rich picture continues.

### **(Stage 3): Root Definition**

Stage 3 enters the systems thinking world where it is intended that the research can create a purposeful situation based on the CATWOE Model. Root Definition (RD) is a structured description of a system with a structure comprising of the elements in CATWOE (see below). CATWOE is a research guide to formulate a formal description described in holons (Checkland, P., & Poulter, J., 2010). Thinking in terms of holons, where things are both autonomous but also connected to greater wholes, is core to systems thinking and may be used to generate defined plausible perspective that can describe real world activities (Checkland, P., & Poulter, J., 2010). It can help formulate possible action labelled as T: 'Transformation' in the CATWOE Model.

The families and parents of PDS are included through the 'Mixed purposeful sampling'. However, the principal researcher did not include with PDS in this



research study. Due to the principal researcher limitation of medical expertise, hence, only families, parents, carers, and the people in the network of support for persons with a disability (PWD) could be included in the interview sessions. Stage 3 is where the process of SSM enters systems thinking world.

The analysis of Root Definition Theme 1 had used the perspectives analysed from Qualitative Analysis. For example, RD Theme 1 uses Perspective no. 1 and so on.

### **RD Theme 1 (CATWOE)**

#### **Perspective no. 1**

**Qualitative data summary:** Participants are concerned that there is no understanding of social and political needs in the network support system. Without this understanding the emancipation of PDS into the community cannot be possible.

**RD holon described in T:** Providing socially inclusive activities in education for PDS rather than providing socially exclusive activities in education.

#### **CATWOE**

<b>Customers</b>	: Person with Down syndrome (PDS)
<b>Actors</b>	: Special education teachers
<b>Transformation</b>	: PDS is socially excluded from education → (replaced by) → PDS socially included from Education
<b>Weltanschauung/worldview</b>	: Individual pedagogical approaches empower PDS to live a sustainable life
<b>Owners</b>	: Malaysian Education System
<b>Environment</b>	: Organisation of professional discipline

**Description of possible system - Theme 1:** Individual pedagogical approaches, provided by special educational teachers for PDS special needs students, are likely to empower PDS to live a sustainable life. Accordingly, Malaysian education system should efficiently organise professional disciplines to include an individual pedagogical approach that may facilitate PDS into a sustainable life.

## **RD Theme 2 (CATWOE)**

### **Perspective no. 2**

**Qualitative data summary:** There were concerns about ‘parent blame’ in providing care to PDS within a supportive network of services.

**RD Holon described in T:** Provide parents with readily understandable medical checklists and guidelines that align with support service provisions rather than providing non mediated materials.

### **CATWOE**

<b>Customers</b>	: Parents with PDS child and carers
<b>Actors</b>	: Rehabilitation Professionals
<b>Transformation</b>	: There is no translated PDS medical checklist guideline for parent and carer support → (replaced by) → there is well translated PDS medical checklist guideline parent and carer support
<b>Weltanschauung/worldview</b>	: Well translated instruction are provided for easy access to information
<b>Owners</b>	: Ministry of Health, Ministry of Education and Social Welfare Department
<b>Environment</b>	: Policy system (Education Policy, Social Welfare Policy, Medical Policy)

**Description of possible system – Theme 2:** When parent and carers can find easy accessible and understandable information recommended by rehabilitation professionals, then it can guide parent and carer support positively. The Ministry of Health, Ministry of Education and Social Welfare Department incorporate information in the provision of well translated PDS medical checklists into the policy system.

### **RD Theme 3 (CATWOE)**

#### **Perspective no. 3**

**Qualitative data summary:** Participants were upset and overwhelmed by the concerns about social status in the care system.

**RD Holon described in T:** An unregulated working environment overwhelms carers and volunteers. A managed care service in which carers and volunteers understand the lack of controlling mechanisms and are not overwhelmed by it, provides a better care service.

#### **CATWOE**

<b>Customers</b>	: Carer and Volunteer
<b>Actors</b>	: Social Welfare Department
<b>Transformation</b>	: Volunteer are overwhelmed to provide care service in an unregulated environment →(replaced by) →volunteer manages care service in an unregulated environment
<b>Weltanschauung/worldview</b>	: Nurturing value and dignity is the essence of a caring society
<b>Owners</b>	: Stakeholders
<b>Environment</b>	: Many types of OKU

**Description of possible system - Theme 3:** When carer and volunteer are not overwhelmed by manage care service in an unregulated environment then social welfare departments are better able to nurture values of dignity. A system that is socially equitable in which stakeholders understand the pressure in an unregulated environment can better nurture for a caring society.

## **(Stage 4): Conceptual Model 1**

The conceptual model (CM) is developed by visualising the holon described in T into verb action, drawing on the possible narratives developed in themes 1, 2, and 3. Conceptual Model 1 was visualised in Diagram 13. To read the Diagrams below, start by reading the visuals diagram from top to bottom.

### **CM in verb action for (Theme 1)**

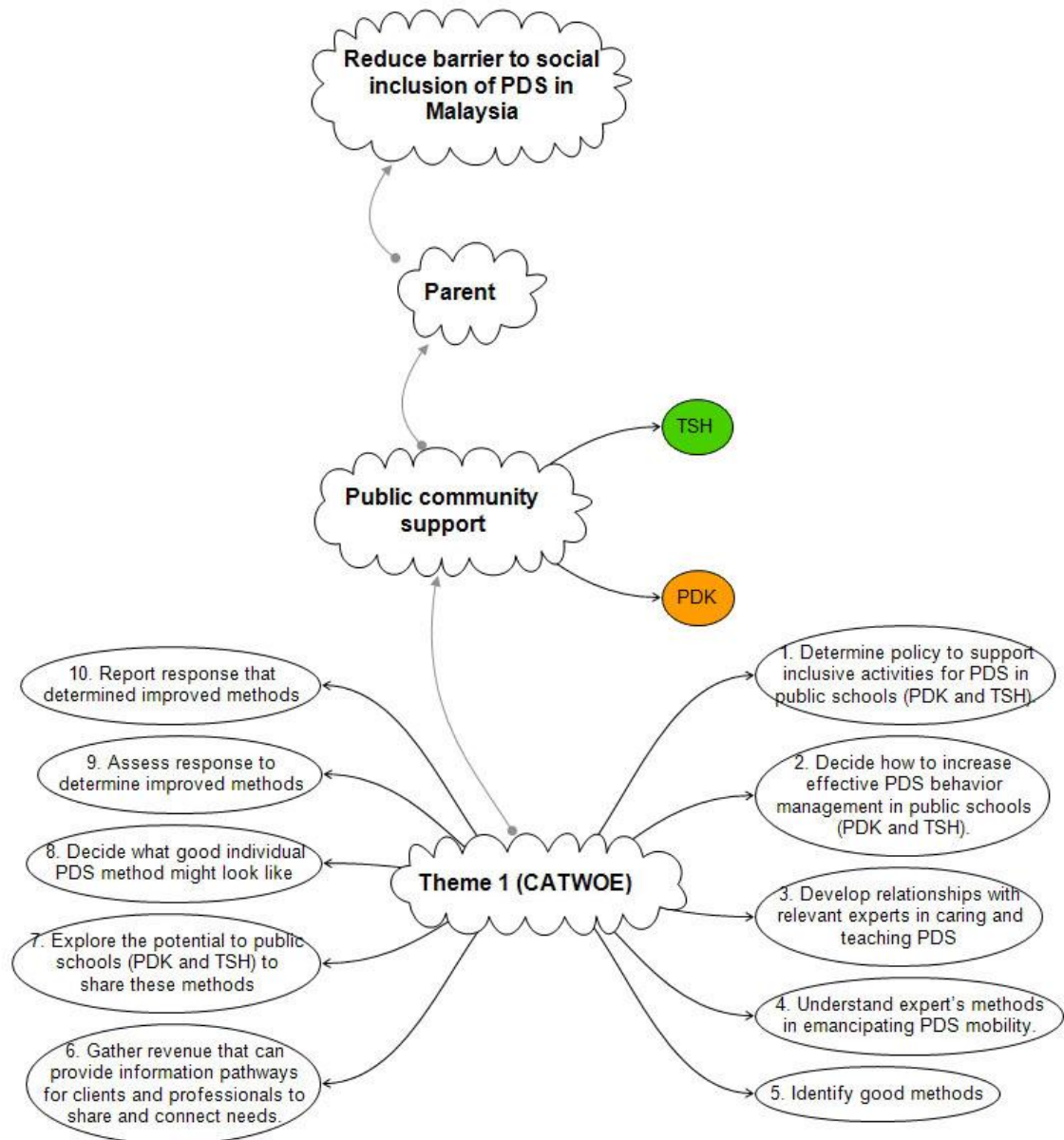
#### **Perspective no. 1**

**Qualitative data summary:** Participants are concerned that there is no understanding of social and political needs in the network support system. Without this understanding the emancipation of PDS into the community cannot be possible.

**RD holon described in T:** Providing socially inclusive activities in education for PDS rather than providing socially exclusive activities in education.

1. Determine the policy to support inclusive activities for PDS in public community support (PDK and TSH).
2. Decide how to increase effective PDS behaviour management in the public community support (PDK and TSH).
3. Develop relationships with relevant experts in caring and teaching PDS.
4. Understand expert's methods in emancipating PDS mobility.
5. Identify suitable methods.
6. Gather revenue that can provide information pathways for clients and professionals to share and connect needs.
7. Explore the potential for public community support (PDK and TSH) to share these methods.
8. Decide what individual PDS method might look like.
9. Assess the response to determine improved methods.
10. Report response that determined improved methods.

**Diagram 15: RD Theme 1 (CATWOE)**



## **CM in verb action for (Theme 2)**

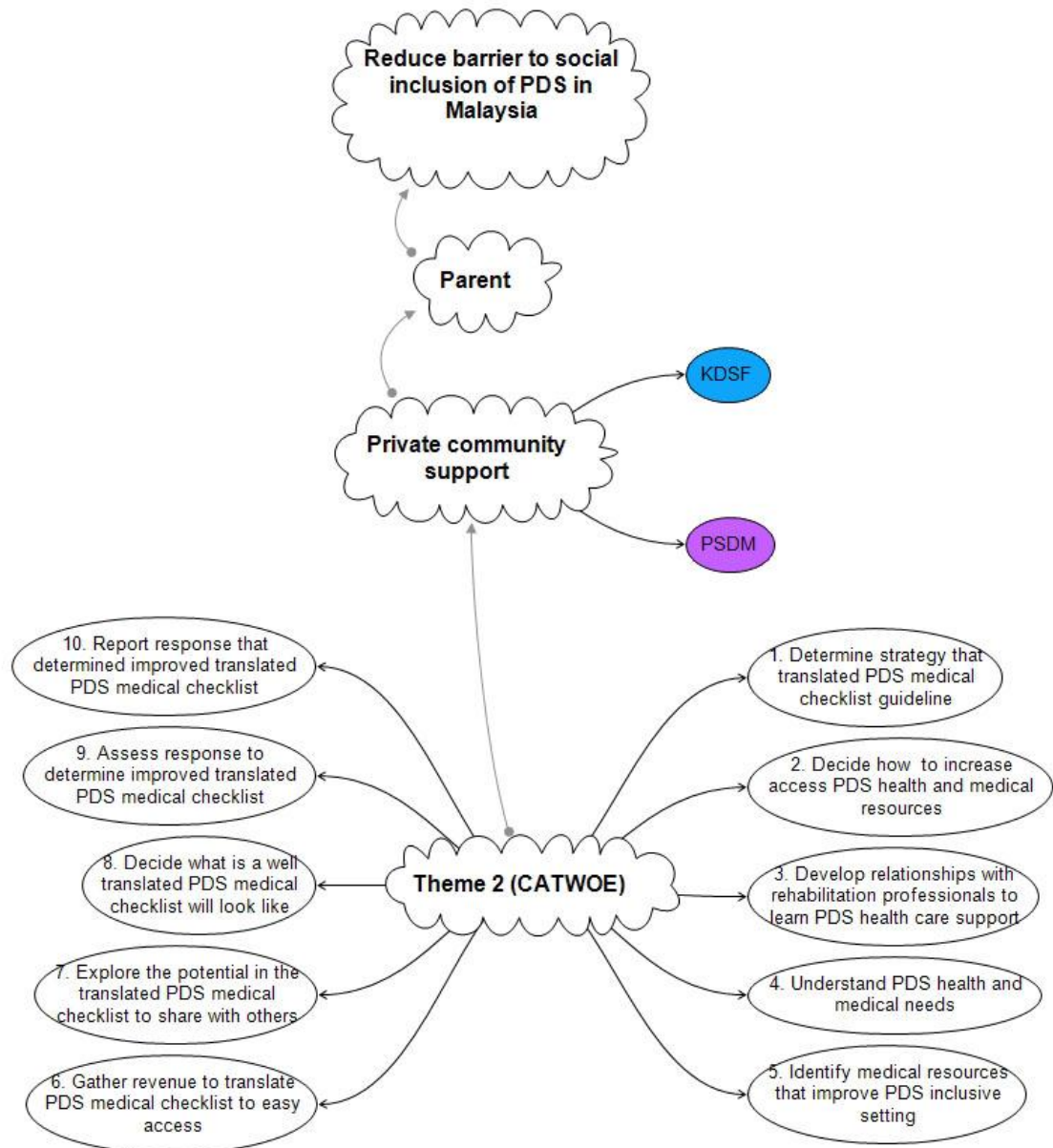
### **Perspective #2**

**Qualitative data summary:** There were concerns about ‘parent blame’ in providing care to PDS within a supportive network of services.

**RD Holon described in T:** Provide parents with readily understandable medical checklists and guidelines that align with support service provisions rather than providing non mediated materials.

1. Determine a strategy that translated PDS medical checklist guideline.
2. Decide how to increase access PDS health and medical resources.
3. Develop relationships with rehabilitation professionals to learn PDS health care support.
4. Understand PDS health and medical needs.
5. Identify useful medical resources that improve PDS inclusive setting.
6. Gather revenue to translate PDS medical checklist for easy access.
7. Explore the potential in the translated PDS medical checklist to share with others.
8. Decide what a well-translated PDS medical checklist will look like.
9. Assess a response to determine improved translated PDS medical checklist.
10. Report response that determined improved translated PDS medical checklist.

**Diagram 16: RD Theme 2 (CATWOE)**



### **CM in verb action for (Theme 3)**

#### **Perspective #3**

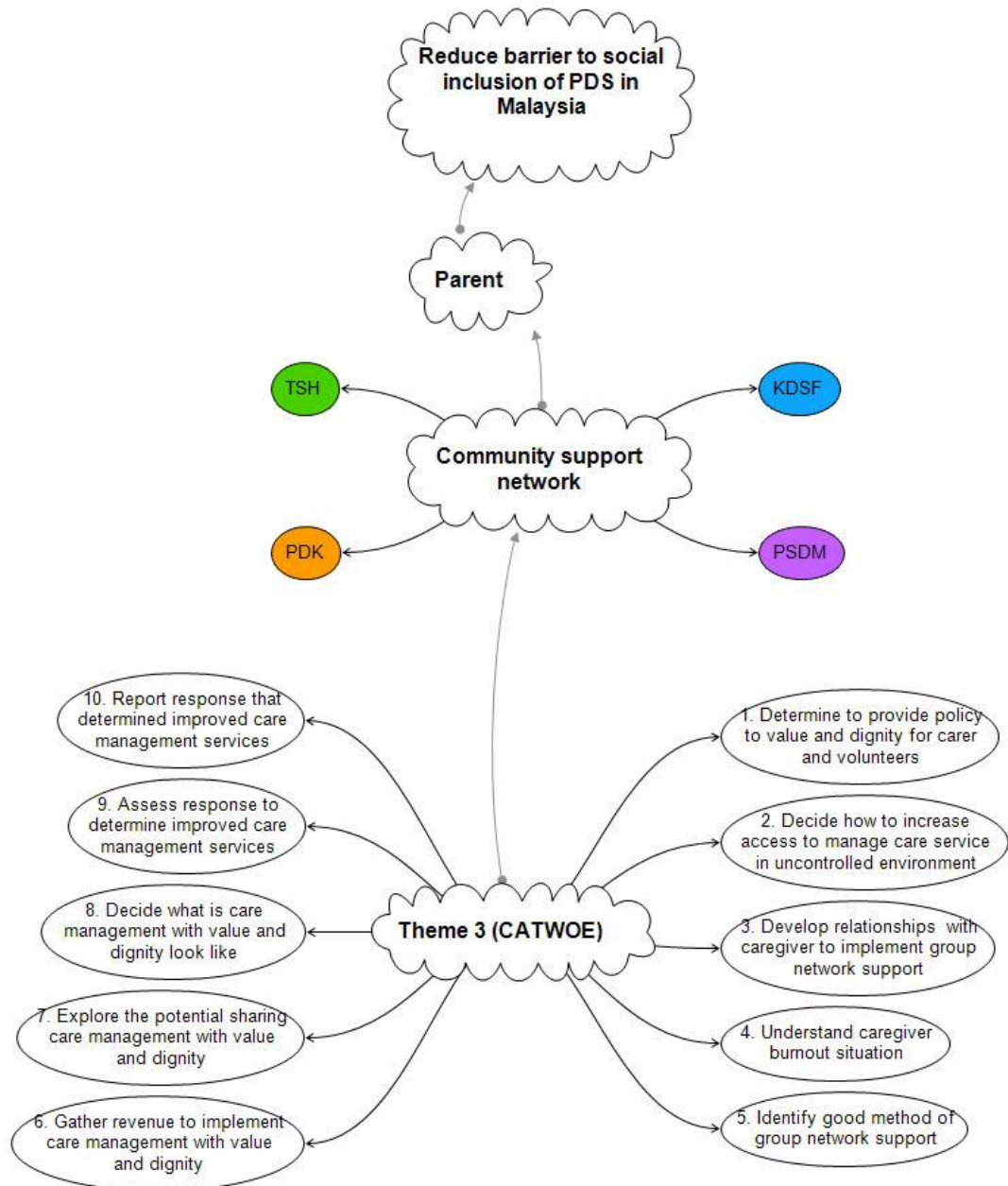
**Qualitative data summary:** Participants were upset and overwhelmed by the concerns about social status in the care system.

**RD Holon described in T:** An unregulated working environment overwhelms carers and volunteers. A managed care service in which carers and volunteers understand the lack of controlling mechanisms and are not overwhelmed by it, provides a better care service.

1. Determine to provide policy to value and dignify carers and volunteers.
2. Decide how to increase access to manage care service in an unregulated environment.
3. Develop relationships with caregiver to implement group network support.
4. Understand caregiver burnout situation.
5. Identify suitable method of group network support.
6. Gather revenue to implement care management with value and dignity.
7. Explore the potential sharing care management with value and dignity.
8. Decide what is care management with value and dignity looks like.
9. Assess the response to determine improved care management services.
10. Report response that identifies improved care management services.



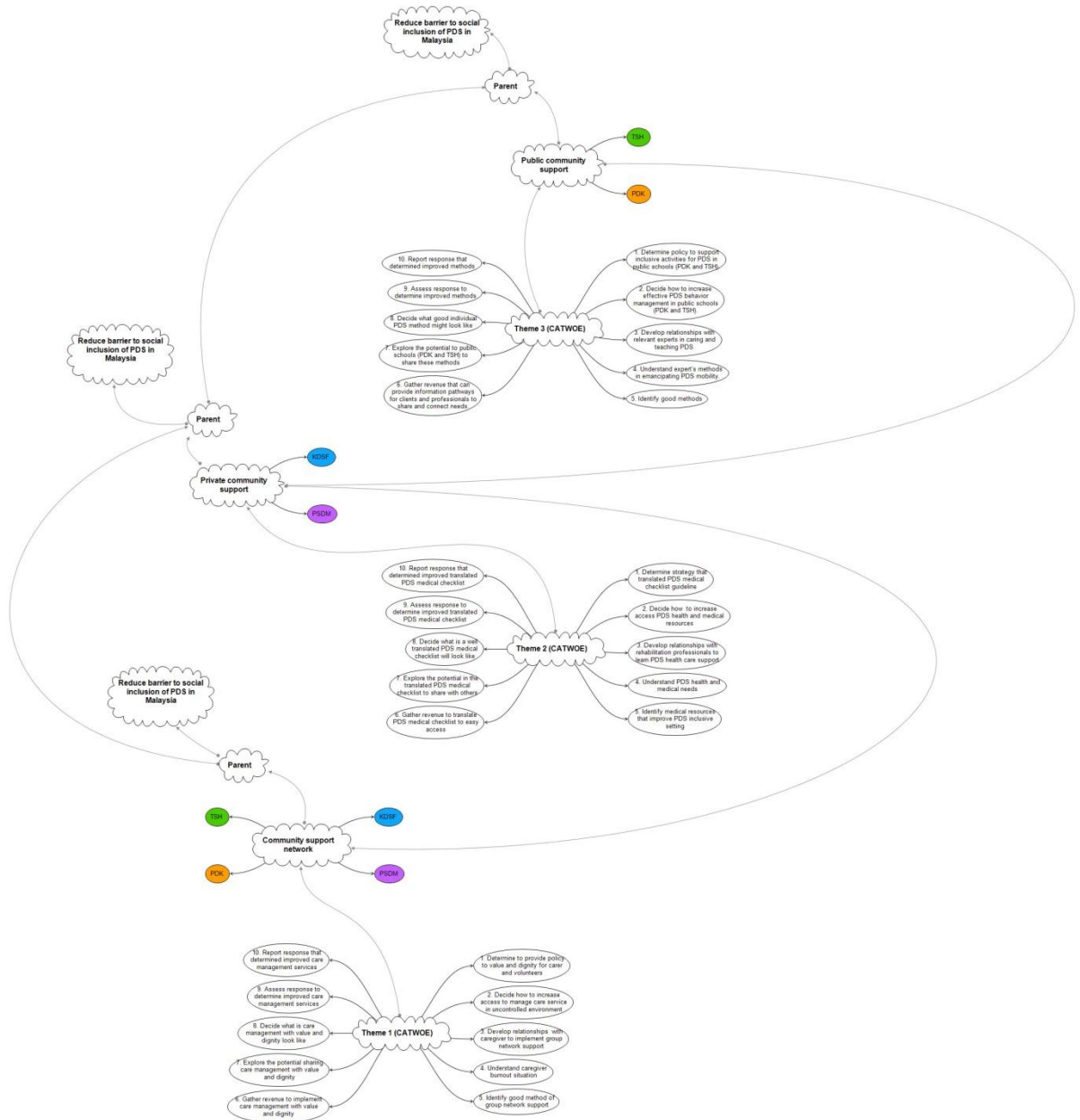
**Diagram 17: RD Theme 3 (CATWOE)**



**Below are Diagram 18 that links Diagram of Theme 1, Theme 2 and Theme 3 (CATWOE)**

To read the Diagrams below, start from reading the visuals diagram from top to bottom.

**Diagram 18: Conceptual Model 1 (CATWOE)**  
**(Large resolution in Appendix A in pp. 218)**



## **(Stage 5): Rich Picture vs. Conceptual Model**

Stages 5, 6 and 7 contribute to Objective 2 of the study.

During Stage 5 and 6 is where systems thinking world goes back to the real world, to define changes that should be implemented. Table 6 below is a comparison of the rich picture the conceptual model

**Table 6: Rich Picture vs. Conceptual Model**

<b>Activities in concept model (Stage 4)</b>	<b>Activities in real world situation (stage 2)</b>			
<b>Description of possible system</b>	<b>Does it exist in the real world?</b>	<b>How does it behave?</b>	<b>How is its performance identified and measured?</b>	<b>Is this process any good?</b>
	<b>Comments built on Theme 1</b>			
Theme 1 → Individual pedagogical approaches provided by special educational teachers for PDS special needs students are likely to empower PDS to live a sustainable life. Accordingly, the Malaysian education system can effectively organise professional disciplines to include an individual pedagogical approach that may facilitate PDS into a	This approach to PDS individual pedagogy has been implemented in KDSF and PSDM. However it is not implemented well in PDK and TSH.	KDSF and PSDM have an assessment system by professional special education teachers to improve PDS student's performance, because they hold a graduation after PDS	PDK and TSH provide care and therapy services, however it has limited services for assessment to increase PDS engagement in education levels.	Special education teachers in Private institution are concerned when the importance of an effective organisation of professional discipline is not understood. Private institutions can provide in-depth support to public institutions in

sustainable life.		student completed highest level of education.		the process of individual pedagogy.
	<b>Does it exist in the real world?</b>	<b>How does it behave?</b>	<b>How is its performance identified and measured?</b>	<b>Is this process any good?</b>
<b>Comments were viewed built on Theme 2</b>				
Theme 2 → When parents and carers understand and can find easy access to information such as a PDS medical checklist recommend by rehabilitation professionals, then PDS medical checklist can guide parent and carer support. The Ministry of Health, Ministry of Education and Social Welfare Department should incorporate information to provide a well translated PDS medical checklist into the policy system.	PDS medical checklists were not well translated for parents with PDS children because parents are required to independently seek out medical rehabilitation support services.	A parent with PDS goes to private or public institutions to gain professional support.	Some parents with access to professional medical support are assessed by medical doctors. Other parents with PDS children that choose not gain access to professional medical support will not be assessed by medical	This process is good because it provides networked services of medical professionals and parents with PDS children. However, it can be difficult for parents that seek self-sustainable support when their child reaches adult age because they do not understand the translated

			doctors.	medical checklist.
	<b>Does it exist in the real world?</b>	<b>How does it behave?</b>	<b>How is its performance identified and measured?</b>	<b>Is this process any good?</b>
	<b>Comments built on Theme 3</b>			
Theme 3 → When carers and volunteers are not overwhelmed and manage care services in an unregulated environment, then the social welfare department is nurturing the value and dignity of the overwhelmed carer and volunteer. Thus stakeholders can understand the pressure in unregulated environment and can better contribute to a caring society.	Actions that promote value and dignity are not implemented well. There are concerns from participant's dues to burnout and stress.	Carers behave as volunteer support services.	Performance of carers and volunteers can be at variance in different institution support services.	This process can be unsatisfying and can be unbalanced in different social status situation.

Efficacy, Efficiency and Effectiveness (3E), further synthesises material. A description of possible systems derived from Themes 1, 2 and 3 follows.

<b>Summary</b>	<b>Efficacy (E1)</b> indicates,	<b>Efficiency (E2)</b> indicates, whether	<b>Effectiveness (E3)</b> indicates, whether
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	<b>whether the transformation provides the intended outcome</b>	<b>the least possible amount of resources is being used to implement the transformation</b>	<b>the transformation helps to realize a more long-term goal (i.e. if it fits into a long-term strategy of the system)</b>
CM Theme 1	Intended outcome involves the integration of special educational teachers into the education system with the responsibility to provide PDS transformation to a sustainable life.	Resources directly applied to individual pedagogic approaches are the only resources that can provide research in developing an effective one to one PDS pedagogy	If experts in departments of health, education and social welfare incorporate their information well, then the departments can develop long term goals of empowerment.
CM Theme 2	Intended outcome involves stakeholder's responsibility to provide transformation to provide a well translated PDS medical checklist into the policy system.	Translating a PDS medical checklist requires resources from rehabilitation professionals and language experts.	If experts in departments of health, education and social welfare incorporate their information well, then the departments can develop long term goals of empowerment..
CM Theme 3	Intended outcome requires stakeholders to	Network support should acquire fewer resources when the	If experts in departments of health, education and social

	develop a transformation of workplace culture to one that nurtures the value and dignity of overwhelmed carers and volunteers	network acknowledges the value and dignity of carers and volunteers.	welfare incorporate their information well, then the departments can develop long term goals of empowerment.
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### **(Stage 6): Desirable and Feasible Intervention (DFI)**

Discussions in stage 6 explore the possibilities of Desirable and Feasible Intervention (DFI). Below are descriptions of a potential system built on the performance of CATOWE as BATWOVE, in which B is beneficiaries and V is victims. BATWOVE will model DFI into 3 themes 1.

#### DFI Theme 1 (BATWOVE)

**Analysis 1:** If intervening in a problem situation described in CATWOE becomes a problem, then BATWOVE is used to clarify a different perspective (Checkland, P., & Poulter, J., 2010). Below describe different root definition of Theme 1 using BATWOVE.

#### **Perspective no. 1**

**Qualitative data summary:** Participants are concerned that there is no understanding of social and political needs in the network support system. Without this understanding the emancipation of PDS into the community cannot be possible.

**RD Holon described in T:** Provide well translated PDS medical checklist guideline for parents support rather than providing no translated PDS checklist guideline.

**DFI Holon described in T:** Public school teachers make the effort to understand PDS pedagogy, rather than neglect it.

### **BATWOVE**

<b>Beneficiary</b>	: Public school teachers
<b>Actors</b>	: Ministry of Education
<b>Transformation</b>	: Public school teachers do not understand PDS individual pedagogy → (replaced by) → public school teacher understand PDS individual Pedagogy
<b>Weltanschauung/worldview</b>	: PDS have a right to education / PDS disability checklist
<b>Owners</b>	: Policy makers
<b>Victim</b>	: Person with Down syndrome
<b>Environment</b>	: Standard pedagogy and PDS focussed individual pedagogy

**Description of possible system - Theme 1:** If public school teachers are required to implement inclusive education in their class, then providing a PDS disability standard checklist could be Ministry of Education model to encourage public school teachers to understand PDS pedagogy. Consequently, a PDS medical checklist could be one of many resources that could improve the educational standard of PDS students with individual needs.

**Analysis 2:** If the culture of the situation is studied from the perspective of social implementation then expected behaviour and beliefs about the value of responses become a social system. Below is a conceptual model of Theme 1 that examines action from a BATWOVE description of a possible system.



### **DFI Conceptual Model**

**DFI Holon described in T:** Public school teachers make the effort to understand PDS pedagogy, rather than neglect it.

### **Perspective #1 - CM in verb action for (DFI Theme 1 - BATWOVE)**

1. Determine a strategy to understand PDS pedagogy for effective teaching.
2. Decide how to increase access to information for PDS teaching resources.
3. Develop relationships with parents with PDS child to understand individual needs.
4. Explain PDS child personal development.
5. Identify useful method that increases memory development.
6. Gather revenue that modify curriculum plan into memory repetition model.
7. Explore the potential in public community support teachers to share PDS pedagogy.
8. Decide what encourage PDS students and other OKU students to learn together.
9. Assess the response to determine improved PDS pedagogy.
10. Report response to established improved PDS pedagogy.

**Diagram 19: DFI Theme 1 (BATWOVE)**



**Analysis 3:** If the expression and examination of power is examined, then the analysis of the situation needs a political resolution. Below is a brief description that compares the rich picture and BATWOVE in Theme 1.

Does it exist in the real world? How does it behave? How is performance identified and measured? Is this process any good?

1. A PDS medical checklist is not provided in the ministry educational model.
2. Educational model uses disability legislation passed in 2008
3. The performance is assessment and measured based on the 2008 disability legislation for OKU students with multiple special needs.

**Summary:** The description of possible system change in CATWOE suggested that an individual pedagogic approach adopted by special educational teachers for PDS special needs students, are likely to help empower PDS to live a sustainable life. The BATWOVE description proposes the adoption of a PDS disability checklist standard, from the Ministry of Education, to encourage public school teachers to contribute to an understanding of PDS pedagogy. Both CATWOE and BATWOVE identified the important role rehabilitation professionals can play in administering a well translated PDS medical checklist.

DFI Theme 2 (BATWOVE)

**Analysis 1:** In intervening in a problem described in CATWOE the intervention itself becomes a problem, BATWOVE is then used to clarify different perspectives (Checkland, P., & Poulter, J., 2010). What follows is a different root definition of Theme 2 using BATWOVE.

**Perspective no. 2**

**Qualitative data summary:** There were concerns about blaming parental contribution to care support. There were also concerns to develop network support services.

**RD Holon described in T:** Provide a well translated PDS medical checklist to support parental engagement rather than provide nothing.

**DFI Holon described in T:** Rehabilitation professionals translate a PDS medical checklist rather than not.

**BATWOVE**

<b>Beneficiary</b>	: Rehabilitation Professionals
<b>Actors</b>	: Parents with PDS child and carer
<b>Transformation</b>	: rehabilitation professionals did not translate PDS medical checklist →(replaced by) → rehabilitation professionals translated PDS medical checklist.
<b>Weltanschauung/worldview</b>	: Stakeholders can overcome situation that supports PDS individual behavioural characteristics
<b>Owners</b>	: Person with Down syndrome
<b>Victim</b>	: Social Welfare Department
<b>Environment</b>	: Funding support

**Description of possible system - Theme 2:** If rehabilitation professionals translated a PDS medical checklist for parents with PDS, then stakeholders can find strategies to overcome PDS individual behavioural situations. In consequence the individual with Down syndrome is involved in the outcomes of the Social Welfare Department funding support systems.

**Analysis 2:** If the culture of the situation is studied, then an examination in terms of cultural implementation then values about expected behaviour and beliefs become acculturated. Below is the conceptual model of Theme 2 that examines action from a BATWOVE description of a possible system.

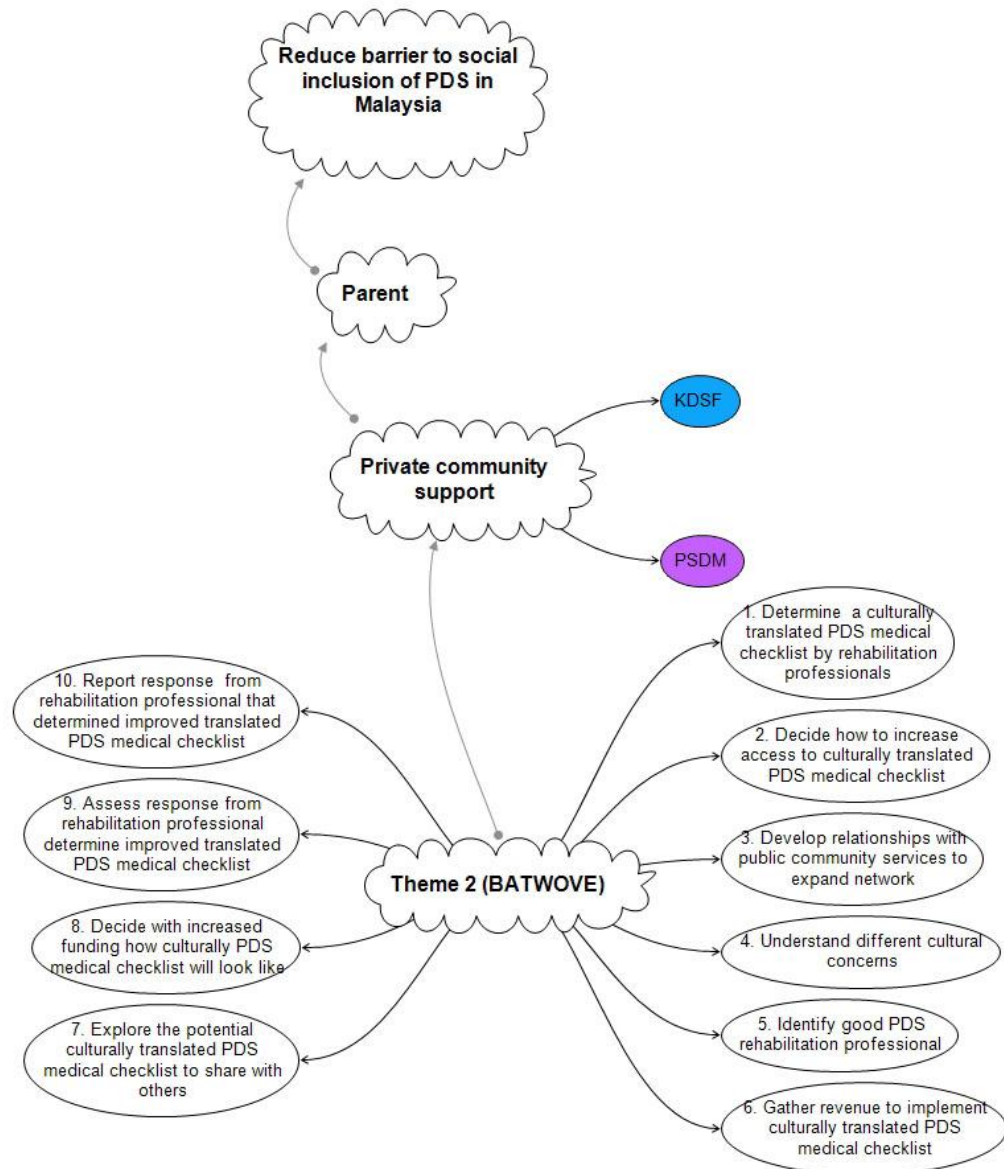
### **Conceptual Model**

**DFI Holon described in T:** Rehabilitation professionals translate a PDS medical checklist rather than not translate a PDS medical checklist.

#### **Perspective no. 2 - CM in verb action for (DFI Theme 2 - BATWOVE)**

1. Determine a culturally appropriate translated PDS medical checklist with rehabilitation professionals.
2. Decide how to increase access to such a PDS medical checklist.
3. Develop relationships with public community services to expand the network.
4. Understand different cultural concerns.
5. Identify good PDS rehabilitation professionals.
6. Gather revenue to implement culturally translated PDS medical checklist.
7. Explore and share the potential PDS medical checklist with others.
8. Decide on increased funding to determine how the PDS medical checklist will look.
9. Assess the response from rehabilitation professionals.
10. Report response from rehabilitation professionals.

**Diagram 20: DFI Theme 2 (BATWOVE)**



**Analysis 3:** If the exercise and expression of power is examined, then analysing the situation becomes political. Below is a brief description that compares the rich picture and BATWOVE in Theme 2.

Does it exist in the real world? How does it behave? How is its performance identified and measured? Is this process any good?

1. A Well translated PDS medical checklist not a priority in the policy system.
2. A PDS medical checklist is provided in KDSF and PSDM support services
3. KDSF and PSDM have the special educational and rehabilitation professionals to assess the situation.
4. This process is suitable for private institutions. However, public schools require more support in terms of translating from health care guidelines for individuals with Down syndrome into educational expertise for teachers in public schools.

**Summary:** The description of a possible system in CATWOE suggested providing a well translated PDS medical checklist in the policy system. BATWOVE explores the description of a possible system in which rehabilitation professionals are required to translate it. Both CATWOE and BATWOVE propose a possible intervention in Theme 2, the identification of rehabilitation professionals to authorise a well translated PDS medical checklist.

### DFI Theme 3 (BATWOVE)

**Analysis 1:** If intervening in a problematic situation described in CATWOE creates a problem, BATWOVE is used that clarify that problem from a different perspective (Checkland, P., & Poulter, J., 2010). Below follows a description of a different root definition of Theme 3 using BATWOVE.

### **Perspective no. 3**

**Qualitative data summary:** Participants were upset and overwhelmed by concerns with social status within the care system.

**RD Holon described in T:** Carers and volunteers who are not overwhelmed to better manage a care service in an unregulated environment, rather than carers and volunteers who are too overwhelmed to provide care.

**DFI Holon described in T:** Unlimited access to experts' resources alongside increased funding, rather than limited access to experts' resources with lack of financing.

### **BATWOVE**

<b>Beneficiary</b>	: Person with Down syndrome
<b>Actors</b>	: Carers and Volunteers
<b>Transformation</b>	: Limited access to experts resources with lack of funding → (replaced by) → Unlimited access to expert's resources with applicable funding
<b>Weltanschauung/worldview</b>	: Self-sustainable services for a peaceful and safe environment.
<b>Owners</b>	: Parents with PDS child
<b>Victim</b>	: Stakeholders
<b>Environment</b>	: Encourage a fund raising model

**Description of possible system - Theme 3:** If there was unlimited access to expert resources and applicable funding, stakeholders could provide a self-sustainable service creating a peaceful and safe environment for PDS. As a result, parents with a DS child could be encouraged to become involved in modelling fund raising activities that can improve services from carers and volunteers.

**Analysis 2:** If the culture of a social situation is studied in terms of implementation in social policy, then beliefs about the value of behaviours become part of social system. Below is a conceptual model of Theme 3 that examines the action from a BATWOVE description of a possible system.



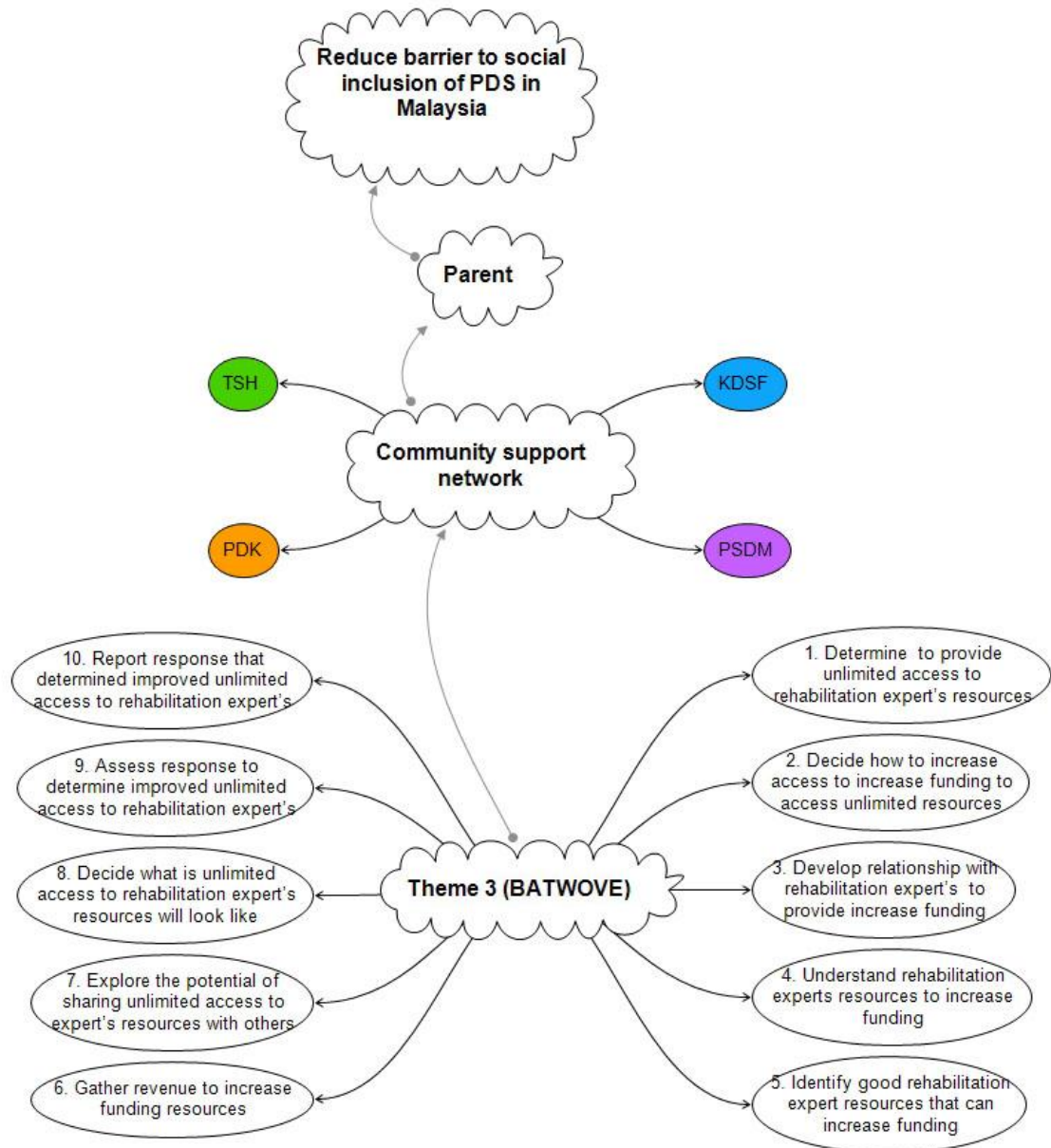
### **Conceptual Model**

**DFI Holon described in T:** Unlimited access to rehabilitation experts' resources and an increase in funding rather than limited access to rehabilitation expert's resources with a lack of funding.

### **Perspective #3 - CM in verb action for (DFI Theme 3 - BATWOVE)**

1. Determine how to provide unlimited access to rehabilitation experts' resources
2. Decide how to increase access to increased funding to access unlimited resources
3. Develop a relationship with rehabilitation experts' to develop increased funding
4. Understand rehabilitation experts' resources in order to increase funding
5. Identify suitable rehabilitation expert resources that can help increase funding
6. Gather revenue to increase funding resources
7. Explore the potential of sharing unlimited access to experts' resources with others
8. Decide what universal access to rehabilitation expert's resources will look like
9. Assess the response to determine improved unlimited access to rehabilitation expertise
10. Report response that determined improved unlimited access to rehabilitation expertise

Diagram 21: DFI Theme 3 (BATWOVE)



**Analysis 3:** If the exercise an expression of power is examined, then the analysis of the problem becomes part of the political system. Below is a brief description that compares the rich picture and BATWOVE in Theme 3.

Does it exist in the real world? How does it behave? How is its performance identified and measured? Is this process any good?

1. Unlimited accesses to experts' resources are available via the internet.
2. Much of the information about experts' resources has been previously disseminated via the internet.
3. It is difficult for a typical parent (of diverse culture) to understand keywords that link to the expert's resources.
4. It is good if the fundraising models that are taught to motivate parental involvement are implemented well and simultaneously support stakeholder dissemination of expertise suitable to the current culture of the community.

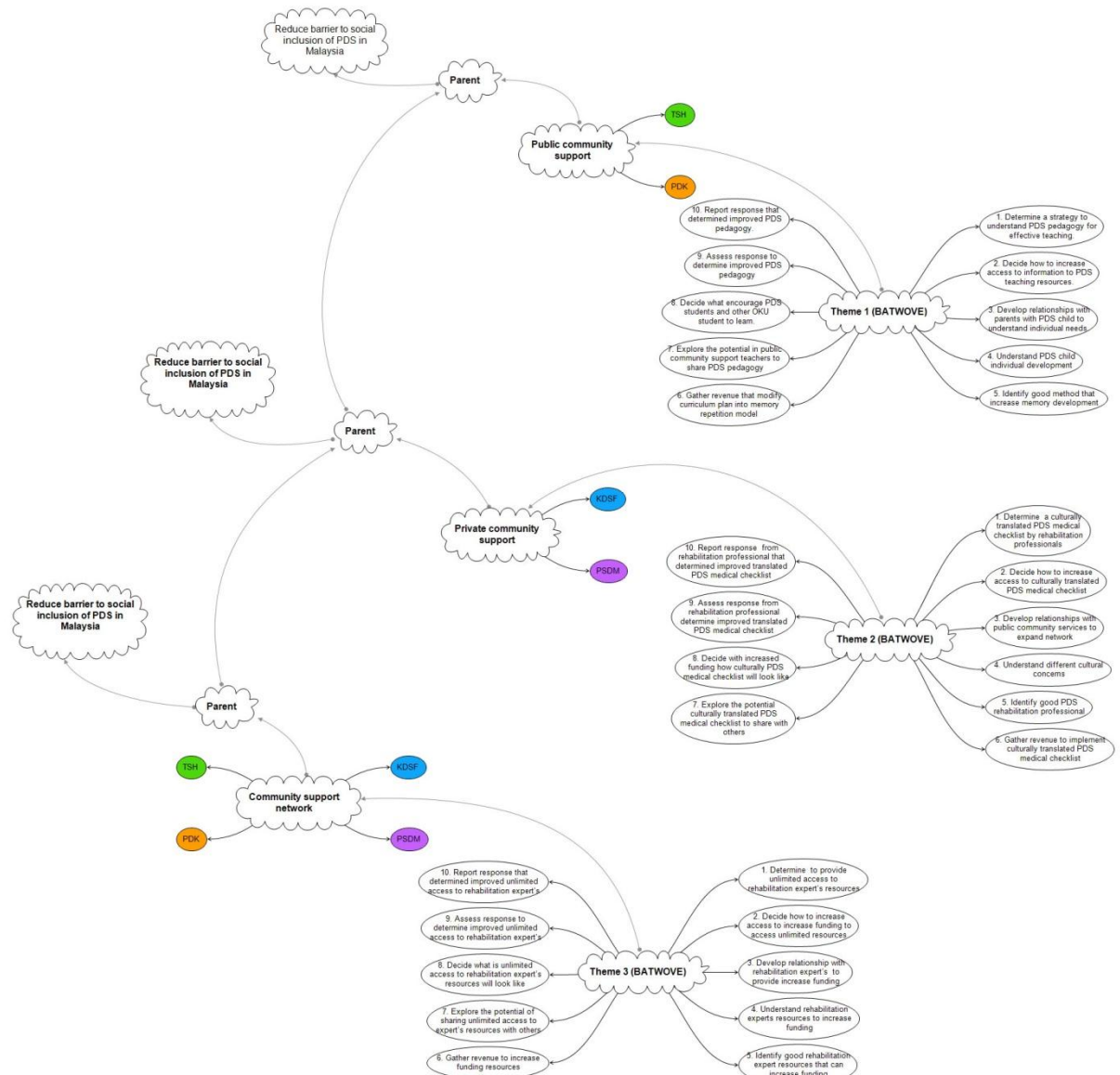
**Summary:** The description of a possible system in CATWOE suggested that it is important to nurture the value and dignity of overwhelmed carers and volunteers. BATWOVE explores a potential system as a fundraising model which could be taught to motivate parents and improve expert resources. Both CATWOE and BATWOVE can empower through possible action described in Theme 3.

## Conceptual Model 2

Below is a Diagram 22 linking Diagram from DFT Theme 1, DFT Theme 2 and DFT Theme 3

To read the Diagrams below, start from reading the visuals diagram from top to bottom.

**Diagram 22: Conceptual Model 2 (BATWOVE)**  
(Large resolution in Appendix A pp. 218)



## **(Stage 7): Action to improve the situation**

SSM Stages 1 to 6 studied potential interventions in the description of possible system materials described in Themes 1, 2, and 3. Participant's concerns displayed in rich picture were examined, and possible actions are presented in Stage 7.

In Stage 7, the SSM comes to a complete full cycle and further possible interventions will continue the cycle through participants' interest in either applying 'possible action' or continuing to review the 'possible action' revealed in stage 7.

### **Possible Action for Theme 1**

- **Qualitative data summary:** Participants are concerned that when there is no understanding of social and political needs in the network support system, then emancipating PDS into the community cannot be possible.
- **CATWOE:** The Malaysian education system could effectively organise professional disciplines to include an individual pedagogic approach that may empower PDS.
- **BATWOVE:** A PDS medical checklist could be one of many resources that can improve the educational standard of PDS students with special needs.

### **Possible Action for Theme 2**

**Qualitative data summary:** There were concerns about blaming parental contribution to care support. There were also concerns to develop network support services.

- **CATWOE:** The Ministry of Health, Ministry of Education and Social Welfare Department could incorporate information to provide a well translated PDS medical checklist into the policy system.
- **BATWOVE:** Persons with Down syndrome can be involved in developing Social Welfare Department funding support systems.

### **Possible Action for Theme 3**

- **Mix qualitative summary:** Participants were upset and overwhelmed by concerns with social status within the care system.

- **CATWOE:** If stakeholders understand the pressure of an unregulated environment experienced by carers and volunteers, then they can realise the importance of nurturing concerns of value and dignity.
- **BATWOVE:** Fund raising models were described as a possible system that could be developed to motivate parents and improve expert resources.

#### **4.5 OVERALL ANALYSIS**

The gap in the knowledge briefly presented the concerns on PDS in the public and private organisation that support Person with Down syndrome (PDS) rights to life in Malaysia. Advocates had argued that inclusive education in Malaysia faces implementation issues and people with disabilities at all levels face exclusion from school. This analysis reveals that participants acknowledge therapies and rehabilitation programmes has possibilities for overcoming exclusionary barriers of PDS. That disability arts education has the potential to succeed when integrated with value dignity.

However, the parental and networked organisational support for a child with DS is critical for PDS to go on to lead an independent life. The importance of having a socially valued network is central to PDS development and learning as is having programmes and activities in disability art education that promote a feeling of dignity and freedom. Drawing from the 'voices' of participants has brought forward the key internal relationships within disability support services in Malaysia and intermittently linked these to the broader external environment. In providing an analysis of the managing bodies of OKU support in Malaysia has revealed concerns of disability that goes beyond the individual is part of a broader social context.

The research has shown how the visual diagrams connect with the various areas of principal institutions including those of the state; disability services provided by civil society, family groups and the disability movement. The analysis and synthesis support the unfolding of the historical contingencies that, in effect, draws out the unique historical and intuitional context of Malaysian disability policy.

The SSM, on the other hand, had displayed the data that is organised and systematically using visual diagrams (including the visual representation of organisational systems of disability support in Malaysia). While visual diagram from Qualitative Analysis were illustrated in a differently perspective because it is designed to Design Thinking model, [p]rototype, which are based on the principals researcher initial process. Both visual diagrams illustrated with Design Thinking model and SSM will display two distinctly different methods of diagrams because of differences research model.

## **CHAPTER 5**

### **Discussion, Conclusion, Future Research And Limitation of study**

#### **5.1 INTRODUCTION**

The research study gathered multiple sets of participant's data from Malaysian stakeholders ranging from parents, carer, medical experts, teachers, and service providers. Both a theoretical and empirical study was linked together in the course of the research findings. A focus on Soft System Methodology (SSM) as a conceptual framework was used (Checkland & Poulter, 2010) to help interpret and apply the data. This was in combination with a mixed method of empirically investigating the relevant literature and gathering data qualitatively through semi-structured interviews. This portfolio of methods allowed a wide ranging analysis and synthesis of participants' views. The data were simultaneously explained between narratives and diagrams. The purpose of this study was to investigate the complex organisational issues that hinder and assist the social integration of PDS in Malaysia and to interpret and visualise those issues through the use of diagrams.

Fresh interpretations of information can be revealed by transferring data into visual diagrams. The researcher of this study was testing the proposition that illustrating a case problem can be a tool for assessing the logical connections that provide a solution to a minor problem claimed by Root-Bernstein in his paper *Problem of Problems* (1982). Horn (1989) developed this point suggesting that the ability to propose a sequence of logically connected problems creates a problem tree that can provide not only the solution to a single minor problem, it is also likely to create a data sequence leading to the solution of an entire problem area.

The researcher firstly gathered data that addressed the study's first objective; to identify and approach which can best demonstrate the characteristics of systems designed to reduce exclusion in the education of people with Down syndrome and to understand the design and systems thinking approaches for improving skills for people with Down syndrome. Secondly, once the data was collected in themed



narratives the SSM, 7 Stage model process was applied to the output of the research study. This was then expressed diagrammatically in multiple sets of design procedure to address the second objective of the study by which, through the use of diagram, seeks to identify existing Malaysian structures that align with the education and empowerment of people with Down syndrome, and evaluate the consequences of design model decisions in explaining the complex system of disability issues for people with Down syndrome.

The researcher understands that to illustrate a case problem (such as this study's visualisation of barriers to the social inclusion of PDS in Malaysia) is not about detecting a solution to a problem. It is rather about resolving the problem's situation, and exploring the problem to reveal alternative solutions to the dominant paradigm. The contribution of the study was to determine how a better understanding of how a complex supports system works, through the use of diagrams. An illustration this case problem has not been undertaken before in the context of design research in Malaysia.

Collecting design research data presented the challenge of designing in a collaborative and interdisciplinary environment (Love, 2000; McDonald, 2006). The data obtained from the empirical study was reviewed, and the result had suggested an explanation of the barriers to social inclusion for PDS in Malaysia. The document analysis and qualitative analysis was conducted with the designer's knowledge in visual practice study. The designers' approach in analysing findings was based on systems thinking and information visualisation and may lead to fresh perspectives about the social and systemic barriers that militate against the social inclusion of PDS in Malaysia. The application of design and systems thinking to social issues is valid if framed through Friedman's definition of design as a generalizable discipline that can be applied to the processes and interfaces in which information is generated collected and disseminated (2003).

Systems thinking methodologies can contribute to future inter-disciplinary or trans-disciplinary study in design research studies and how they intersect with the social realm.

## **5.2 DISCUSSION**

The following discussion about illustrating the case is in three parts. Firstly, a discussion around the document analysis is followed by some observations about the qualitative research process. Finally the way in which SSM transforms data is recapped.

### **5.2.2 Illustrating a case**

There were two parts in the researcher's approach to illustrating a case. One was the discussion of the findings from document analysis. The other was a discussion of findings drawn from qualitative analysis. The study assumed that illustrating a case problem through diagram can connect information together to provide tools to identifying organisational and strategic links to be used by end users in the social realm.

### **Document Analysis**

The research was founded on the principle that visual diagrams can illustrate and help the analysis and development of social phenomena. Diagrams are already used in the business community to great effect. In *Design Thinking Business Innovation* Vianna (2012) writes about the design thinking process, 'After the data collecting stages... the next actions are analysis and synthesis of the information obtained ... arranged to form patterns posing challenges that will assist in clarifying the problem (Vianna et al., 2012 pp. 65-87).

The document analysis produced an overview of the disability support services in Malaysia that was turned into a diagram. The diagram presented a series of logical connections between partners, and the responsibility of organisations towards disability support services, particularly in Down syndrome support (see Chapter 4, Diagram 11, p. 133). Based on the document analysis of official material produced by PDK, TSH, KDSF and PSDM the diagram revealed the institutional background of care services and how they are networked. This overview was

designed with the intention of framing later discussions with participant interviewees.

Examining the impact of the identification of the characteristics of existing programmes and activities can help reduce the exclusion in education of PDS will have to be tested in further research. What the research has done is to extract from a multitude of resources a coherent set of diagrams that illustrate services provided by the institution.

The solution of an entire problem area include the assumption of visual diagrams can identify the barrier to social inclusion of PDS in Malaysia.

The task of collating information in visual form is not, of itself enough to contribute to the presentation of information into the social realm of end users. Without a deeper immersion into the social realm that generates meaning a designer's interpretation of information may simply reflect their own tacit understandings both of the issue, and how they may be represented visually as implicit knowledge is linked to an individual experience rather than to organizations (Puusa & Eerikäinen, 2010). To research design solutions without a grounded methodological design research framework - that is to simply apply already existing design solutions, rather than to let the design solution emerge from data - is a fundamentally flawed approach and any findings, visual or otherwise can be easily contested. Thus, a diagram drawn from solely document analysis alone cannot in itself identify the barriers to the social inclusion of PDS in Malaysia. As Kimbell (2011) has observed there are some design professionals that take solving complex social issues as their practice. For example, policymakers are told that public services should be more user-centred (Parker and Heapy, 2006 in Kimbell, 2011 pp. 286); Businesses engage with customers by offering new meanings for things (Verganti, 2009 in Kimbell, 2011 pp. 286); The US Army is considering the role of design in warfare (School of Advanced Military Studies, n.d.); for design firms working for global clients in relentless pursuit of new markets, new offerings, and new kinds of value creation, design itself is being remade (Tonkinwise, 2010 in Kimbell, 2011 pp. 286), "often but not always working in close collaboration with specialist in public services from healthcare to

those working with disadvantaged families' (pp. 286). Love, (2000) recommends praxis as the only way forward for the designer engaged in representing social phenomena, clarifying relationships between individual concepts and theories, and between these different concepts and theories and their underlying assumptions.

## **Qualitative analysis**

Engaging with end users is an important part of praxis. To this end the study assumed that theoretical data collected in the study needed to be simultaneously embedded in amongst social narratives that made claims about the social inclusion of PDS in Malaysia. Qualitative data were collected through purposeful sampling procedures that included semi-structured interviews and snowball sampling. This aspect of the research became important in enriching and triangulating the data already collected.

Data gathered from semi-structured interview were then themed.

### **Theme 1**

The concept of art education, and art making, was considered as a way to develop problem solving skills for PDS. Emerging from the findings gathered from the discussions with parents, stakeholders, social workers, and teachers it became clear that learning art does help an early development of the brain of PDS. Other participants indicated that art-based programmes were not the only methods that can contribute to memory or brain development of PDS.

The data gathered in theme 1 provided significant information that explained the barrier to social inclusion of PDS in Malaysia. However, participants claims are based on their personal experiences and their claims can be a subject to the bias of their own experiences.

### **Theme 2**

The findings in theme 2 discussed the issues surrounding parent blame. Document analysis had suggested that many parent groups are informal and do not

have well-defined systems for receiving and acting upon referrals from health, education, and human/social service agencies (Levitz & Schwartz, 1995). While another suggested that parents were cautious about inclusion (but not demotivated) because of fears that their child would be badly treated by other students (Elkins, Kraayenoord, & Jobling, 2003; Thompkins & Deloney, 1995). Parent stereotype A is the motivated parent who is able to advocate for the emancipation of their child with DS. Parent B is demotivated and unable to advocate. However, these binary claims are questionable and were subjected to a wide range of discussion from the body of stakeholders, institutional and non-institutional.

These claims made in discussion and organised in theme 2 provide significant information that in part explained the barrier to social inclusion of PDS. Subjective narratives are revealing but have to be placed in relation to one another and against objective information. The personal narrative, because it arises out of discursive practices where the subject is acted upon but also acts, is excellent at revealing the self and its experiences, but it needs to treat with caution when used to define the circumstances in which the self is constituted (Zahavi, 2007).

### **Theme 3**

In theme 3 the social inequalities in the labour force and their consequences were gathered together. Worker burnout, the social segregation of workers and accusation of elitism were all examined through a framework partially suggested by Jayasooria's study that suggested that some organisations that support people with disability were perceived as being elitist because of intrinsic aspects of their organisational structure (1997).

Volunteers' narratives revealed they can be overwhelmed by their work load. The claims can be useful, yet, require other supporting evidence. This evidence came from other indications of social inequalities in the provision of educational support in both the public and private sector. The vast difference between the support for PDS from the public sector and private sector indicated suggested that disability policy and special education contradicted the goals of providing equal educational

opportunities as stated in the UN's ruling for the equalisation of opportunities for PWD (1993), the Salamanca Statement (1994) and the Biwako Millennium Framework for Action (UNESCAP, 2002).

A struggle for equal rights is still evolving in Malaysia, as policy makers and schools put into practice their interpretation of what they perceive those rights to be (Jelas & Ali, 2012). A specific focus on rights of education in the context of the lifespans of people identified with intellectual disabilities has not been prevalent in much of the research literature in Malaysia, despite the growth of local programmes (Adnan & Hafiz, 2001; Jelas & Ali, 2012).

The claims articulated in theme 3, as in the previous two, provided significant information that helped explain the barriers to social inclusion for PDS. The next stage in the visualisation of the information was to subject the narratives to claims against which the narratives could be re-constituted and re-contextualised.

### **5.2.3 Soft Systems Methodology**

SSM uses a system approach to reframe and reconstitute data through the use of questions. The principle is that a dialogue between systems/models and data from the social realm can enhance the ability to understand data by re-focussing. This in turn provides systems clarity and the potential to improve social circumstance. The seven stage process laid out in the previous chapter allowed for the problem to be transformed from one based around the researcher and the problem into a series of analyses that allow for intervention on behalf of the user of the finally realised diagram.

## **5.3 CONCLUSION**

Problems in the social realm are never solved, but what the systems designer can do is to gather data, expose structures, re-arrange the mundane and try to facilitate alternative ways of thinking and acting. In the case of this research project, claims that have emerged from a document analysis and from interviewing stakeholders have been visualised to identify existing approaches and provide an armature in order to improve PDS skill set and thus facilitate social empowerment.

The purpose of this research was assembling complex, disparate procedural strands and experiences in order to see the image of the whole emerge. As Senge (1990a) argued, systems thinking are a discipline for seeing wholes. Systems thinking can facilitate the development of frameworks for seeing interrelationships rather than discrete things, for seeing patterns of change rather than static snapshots. Flood (1999) qualifies this by saying that the researcher should be cautious before rushing into rationalisation of the particular and lose touch with the notion of wholeness. Traditional problem-solving creates a false understanding of the management and organisation by suggesting that identifying a problem and implementing solutions are easily kept under control (Crouch & Pearce, 2012, pp. 19-21). In conceptualising complexity, problem solvers must grapple with complex interrelationships and emergent behaviour that is inherently unknowable. In this way multiple approaches can be gathered together and the synergies of relationships understood. A decision by specialist stakeholders to have a PDS medical checklist translated into a form understandable by non-specialists has the potential to effect huge changes in the emancipation of whole families with a PDS member. Visualising 'action procedures' can assist in preparing, a potential solutions to issues surrounding social inclusion of PDS.

The outcome of this research study did not look for a problem to be solved, rather to exploring the issues diagrammatically to reveal alternative readings of the accepted paradigms. It attempts to gather all the knowledge and reinforce that there is no particular recipe for creating new proofs. The design thinking process reflected the complex inquiry and learning that designers undertake in a systems context (Brown, 2009). Decisions were made as the system developed. The designer worked collaboratively within social teams and their processes with several languages to manage. The design methodology had to be able to reflect different narratives and synthesise the gathered data.

Consequently, the design model of this research study involved multiple sets of design procedures in order to comprehend the analysis and synthesis the output. The visual diagram helps provide not a solution but a visualisation of relationships that may visualise the case problem situation. This procedure helps thinking about

problem-solving beyond 'requirements'. For example, systems thinking and illustrating a case with a diagram plausibly becomes an interrelated communication design model. The process also helps the researcher understand the context(s) required to be recognised. Furthermore, the nature of systems thinking helps keep the researcher on top of perceived changes to the case problem contributing to processes of review and revision. SSM can plausibly provide a cyclical approach that can recognise inter-dependent, multi-modal praxis (Checkland, 1981).

With the integrated methods of design thinking and system thinking procedure can suggest an alternative approach. The combination of design thinking and systems thinking can deliver a holistic understanding of a current system of barrier to social inclusion of PDS in Malaysia. These combined procedures can generate ideas and provide a solution that can transform a system while maintaining the tradition of the systems, thus ensuring a new system is sustainable. The combined procedure can provide an alternative to a more disruptive, strategic planning of looking at problems. In this way stakeholders in Malaysia can continue to understand the care system further through a network of support already in place. It is not necessary to restructure entirely to facilitate institutional change systematically. The systemic process may contribute to studies in an interdependent/trans-disciplinary study.

This project reveals that opportunities for change in the support of people with DS in Malaysia are first and foremost in the provision of the appropriate educational programmes for people with Down syndrome. It is necessary to align learning and skills development with the cognitive and physical limitations of the syndrome. In the field of DS support process there is limited knowledge of how society and stakeholders respond in relation to the inclusive education. It includes Malaysia's disability policy in terms of policy practice (Jelas & Ali, 2012). According to Kiernan there is a growing realisation of the importance of employment for people with DS. There is also an increasing recognition that the process of obtaining a job requires identifying the vision and expectations of the individual with a disability and matching that view to the work and social requirement of the job. It includes the support of on-site training, technology in the workplace, job redesign



and accommodation, and the involvement of co-workers and supervisors as both trainers and support resources. These are strategies that have been effectively utilised to assist persons with severe disabilities in realising their employment goal (Kiernan, 1995). These concerns were discussed with interviewees during the research as a way of building a broad context for the central focus of the project. This project is primarily design research in the social realm rather than a piece of social studies, although the two do closely entwine.

This research recognises that disability issues in the Malaysian are experiencing complexity and that there is a need to have a systematic process to understand it. To map out a visual information approach is useful to this research because it helps to present complex data and frames the issues surrounding the complex Disability Movement in Malaysia. A mapping information approach can improve communication among the different organisations and disciplines of this research. By recognising complexity and interrelated challenges presenting them in a structured visual diagram assists stakeholders, families of PWD and people with Down syndrome. In this way, the options for stakeholders then become truly multimodal.

## **5.4 FUTURE RESEARCH**

The future development of this study can broadly provide further exploration of design thinking within the social realm to present the unknowable, organise within the un-organised and manage within the unmanageable, resolving it into a visual diagrammatic model (Flood, 1999) in order to facilitate social change. It can contribute specifically to the real world and conceptualising of models to support Malaysia's vision and mission of the year 2020 (Mohammad, M., 1990). Finally it can continue positioning of design research in an inter/trans-disciplinary realm.

Malaysia has faced much structural complexity in translating and implementing inclusion policy (Jelas & Ali, 2012). In turn, this has created a structure that is unfocused and unorganised, which can work against systematic inclusion, thus impacting negatively on people with intellectual disabilities (Lee,

1999). This research discussed the factors of social exclusion of people with Down syndrome in Malaysia, contributing to the discussion visually which can plausibly continue to provide support for disability policy making in Malaysia.

Future researches can strategies to employ and gain access to more detailed population demographics. Not employing probability sampling limitation has been a limitation of the study. Future significance would lie in extending research into the philosophy of design to include more fully social methodologies to enrich the efficacy of visual representations of complex social systems and practices.

The concluding significant ambition of this research into design studies is to contribute to the Malaysian national Vision 2020 (Mohammad, M., 1990), which aims to achieve a self-sufficient industrialised nation by the year 2020. The objective of the vision includes aspects of life, economic prosperity, social well-being, world class educational system, political stability and psychological balance. The concept in Vision 2020 is relevant to the research of study because of the challenges in achieving the objective of the study is setting a fully caring society (Human Rights Watch, 2010).

## **5.5 LIMITATION OF STUDY**

This study used mixed purposeful sampling. It included snowball and purposeful random sampling. It used qualitative research design principles rooted in design and systems thinking. It did not employ probability sampling techniques, opting for non-probability sampling techniques instead. (Research Strategy, 2012).

Not adopting probability sampling technique is the key limitation of method in this study (as is the researcher's moving between the design and social research field). A failure to use probability sampling techniques can significantly limit the researcher's ability to make broader generalisations from their results (i.e., the capacity to make statistical inferences from the sample to the population being studied). This in turn limits the study's ability to qualify itself as a grounded study. The recruitment of the sampled 29 participants in the study was a mixed purposeful sampling attempting to link the multiple interests and needs of participants in the

Malaysian care system. The process employed the combination of purposeful random sampling and a snowball sampling strategy (Huberman & Miles, 2002) in establishing setting and grouping.

**Table 1: Participant Setting**

<b>Malaysia</b>
<ul style="list-style-type: none"><li>• Taman Sinar Harapan, Cheras (TSH)</li><li>• Pemulihan Dalam Komuniti, KL (PDK)</li><li>• Persatuan Sindrom Down Malaysia, Ampang (PSDM)</li><li>• Kiwanis Down syndrome Foundation, Subang (KDSF)</li><li>• Cheshire Home, Gombak</li><li>• Independent Families</li></ul>

**Table 2: Participant Groups**

<b>Participant Groups</b>
<ul style="list-style-type: none"><li>• Teachers</li><li>• Carers</li><li>• Parents</li><li>• Social workers</li><li>• Service Providers</li><li>• Volunteers</li><li>• Medical Professionals</li></ul>

Individuals with Down syndrome were not interviewed as part of the project; the researcher is not a medical expert and does not have the legal right to interview PDS individually. Because of this, identifying an initial range of likely stakeholders was essential in then facilitating snowball sampling. As Singh (2008) has identified, a significant challenge to disability issues in Malaysia lies in the lack of uniformity in the staffing and provision of services. Within this context trying to determine key participants was difficult, hence, a broad range of stakeholders such as parents, carers, and the people in the network of support for people with a disability (PWD) were included in the interview sessions in order to try and address as broad a

representation of the social and economic demographics engaged in the support networks as was possible. It was considered important to involve a broad range of participants without preconception as such a practice can identify cultural problems within an organisation (Owen et al., 2009). For this study, the range of stakeholders provided information-rich data from throughout the participants' networks (See: Chapter 3, pp. 94).

The reason for purposeful random sampling is to manage a study's sample size and to offer the researcher a way of discovering information through non-systematic ways, decreasing the influence of the researcher in framing information (Onwuegbuzie and Leech, 2007). When determining sample sizes for qualitative research, the estimated sample size recommended by much qualitative study is 20-30 people, but Guest, Bunce, & Johnson suggest that this is an excessive number and that after interviewing the 10th participant, researchers often realise that there are no new concepts emerging. They suggest that choosing smaller sample groups resolves problems of redundancy (Guest, Bunce, & Johnson, 2006). This study used a small sample group, as the research intention was to establish the credibility of ideas within the discourse about the system, and not to make quantitative judgements about them (See: Chapter 3, pp. 94). This research study began by identifying one influential participant who was involved in the managing body of private and public disability support services in Malaysia and subsequently expanded its scope through mixed purposeful and snowball sampling (See: Chapter 3, pp. 96). Snowball sampling's limits lie in its intuitive origins, it is not empirical. This study used snowball sampling in order to identify extreme or divergent case problems. This process could falsely suggest a consensus in the field in a set of case problems if used exclusively.

Mixed methods have been used to try and circumvent this kind of distortion of data and interpretation. The fields of design research and philosophy of design are still young in the area of theoretical research. Using design to interpret raw data in a complex case such as the twinned issue of PDS rights and understanding barriers to social inclusion in Malaysia positions itself in the contextual ambiguity of 'practice' and 'theory'. It is this concerns as to the value of praxis that led to the development of theories concerning mixed methods in design research (Love, 2000). Love (2000)

recommends the importance of clarifying relationships between individual concepts and theories, and between different concepts and theories and their underlying assumptions. Kimbell (2011) voices a similar concern and further suggests ‘[t]here are some design professionals that take solving complex social issues as their domain, often but not always working in close collaboration with specialists in public services from health care to those working with disadvantaged families.’ (See: Chapter 2, pp.81).

Purposeful random sampling may simply reflect the prior concerns of the investigator (e.g., people, cases/organisations, events, pieces of data) and this process can be lead to judgmental, selective or subjective sampling. Love (2000) proposes that in restructuring design research with the framework of the social sciences ‘What remains needed is ... structuring existing concepts and theories to bind the unnecessary growth in abstraction and terminology ... so that it is clearer to a design researcher which concepts, theories and theoretical strands are pragmatically more useful or better justified, and what their relationships are to each other.’ (See: Chapter 2, pp.82).

## **APPENDIX A**

### **LARGE RESOLUTION VISUAL DIAGRAM**

1. Diagram 5: Public and private support for PWD (See: Chapter 4 pp.127)
2. Diagram 11: Malaysia Disability support service linked in Diagrams (See: Chapter 4 pp.133)
3. Diagram 14: RICH PICTURE Diagram for Theme 1, Theme 2 and Theme 3 (See: Chapter 4 pp.169)
4. Diagram 18: Conceptual Model 1 (See: Chapter 4 pp.182)
5. Diagram 22: Conceptual Model 2 (See: Chapter 4 From pp.200)

# Diagram 5: Public and private support for PWD

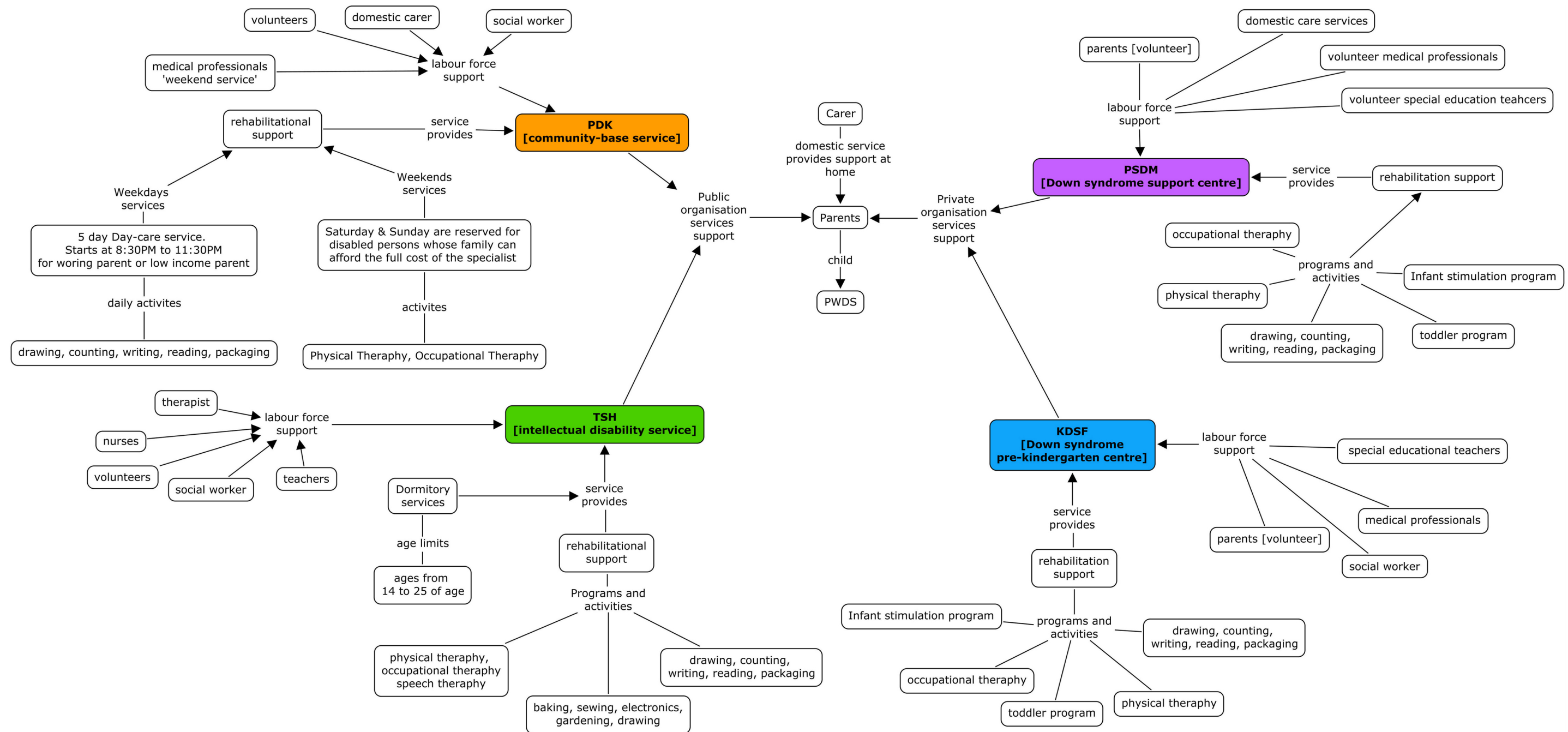


Diagram 11: Malaysia Disability support service linked in Diagrams

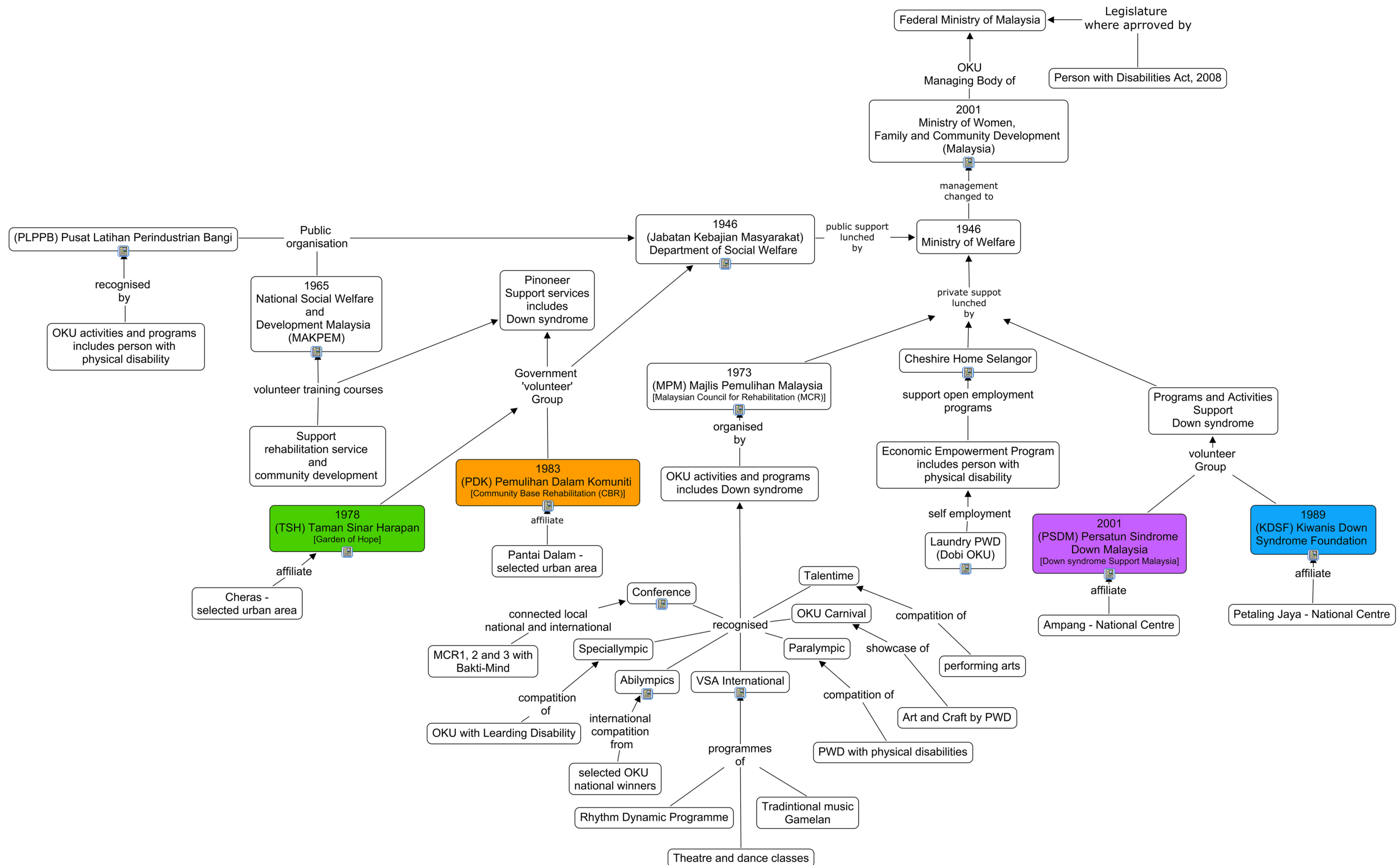




Diagram 14: RICH PICTURE Diagram for Theme 1, Theme 2 and Theme 3

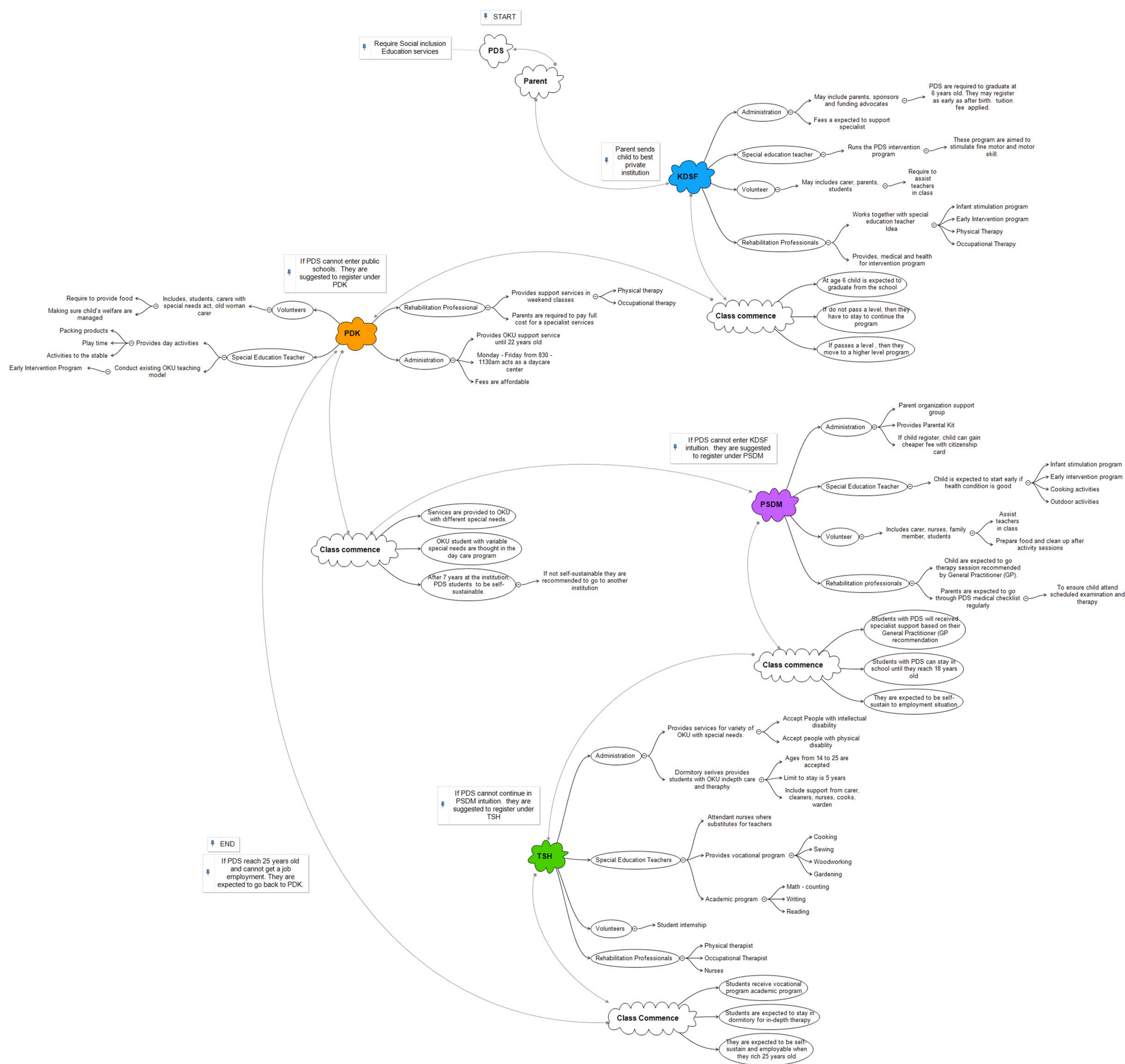
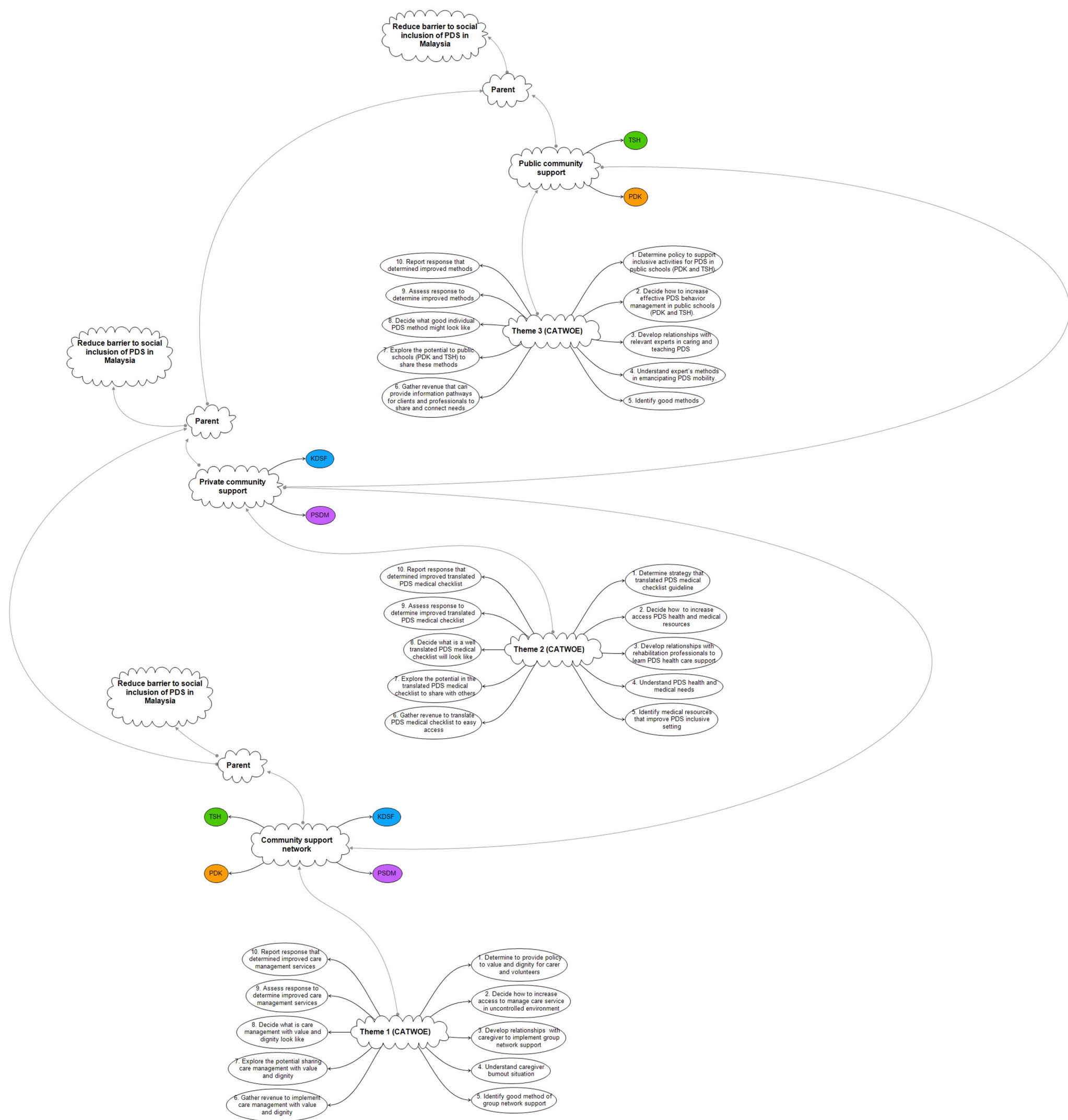
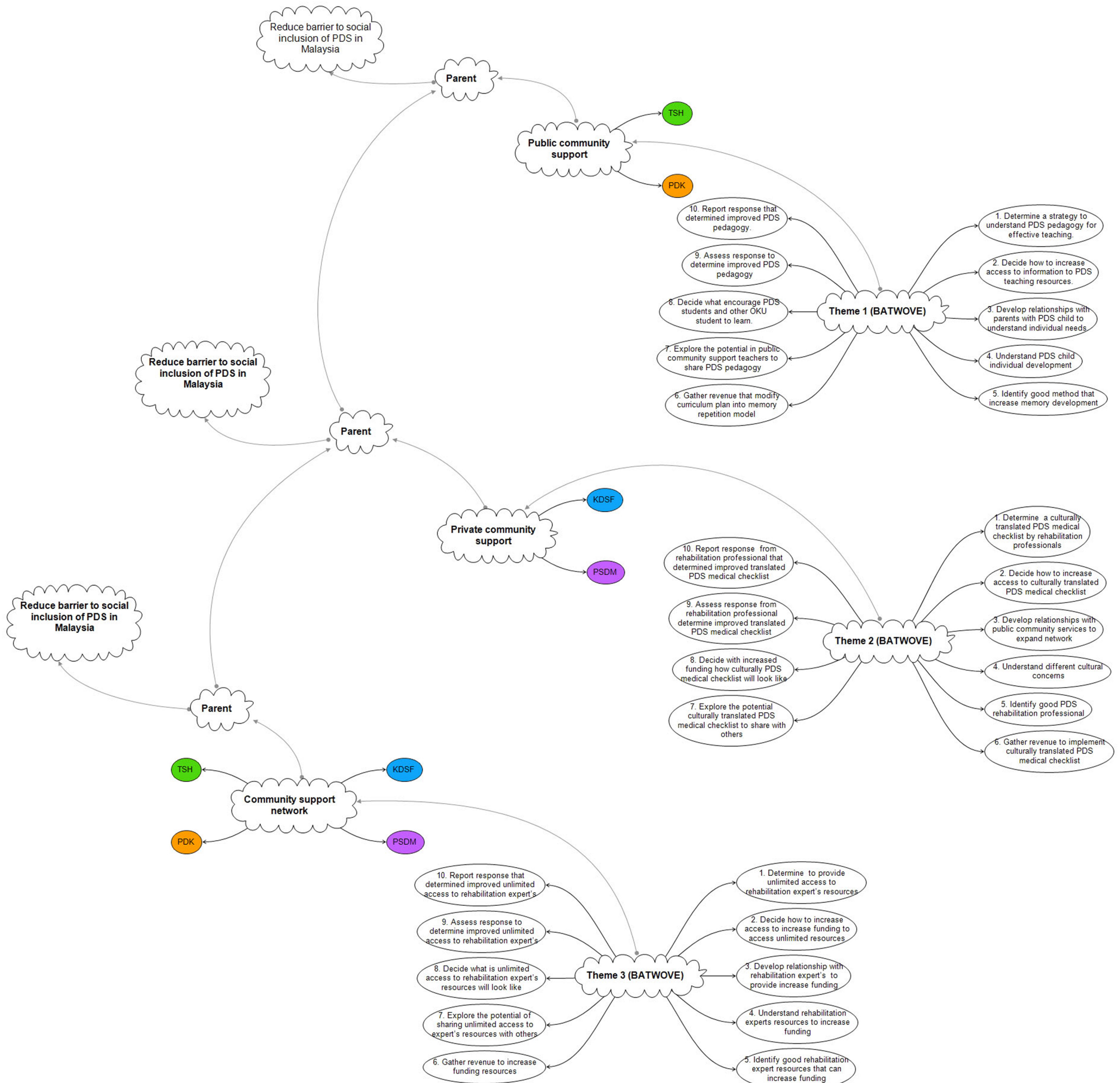


Diagram 18: Conceptual Model 1 (CATWOE)



# Diagram 22: Conceptual Model 2 (BATWOVE)





## APPENDIX B

### CODE BOOK

Col. no.	Q. no.	Variable name		Response Pattern		Code	N o.	Code Site	Code Region
		Stakeholder Position	Acting Position						
1 > 29	1.1	Social Worker	Social worker and PWD Trainer	INTP1	1	PDK	MY		
		Carer	Carer and PWD Trainer	INTP2	2				
		Service Provider	Manager	INTP3	3				
				INTP4	4	UPM			
		Medical Professional	Researcher and Nurse PhD			Health Care			
		Service Provider	Vice president at (Cheshire home) and Hon. Secretary of MCR (volunteer)	INTP5	5	CH			
		Parent	Parent and curriculum Coordinator (volunteer)	INTP6	6	PSDM			
		Parent	Parent and treasurer coordinator (volunteer)	INTP7	7				
		Carer	Carer/Social worker 1c	OPC1	8				
			Art	INTP8	9				
		Volunteer	Professional/Volunteer						
		Parent	Parent	INTP9	10				
				INTP1	11	KSDF			
		Teacher	Teacher	0		(Petaling Jaya)			
			Coordinator and Social	INTP1	12				
		Social Worker	worker	1					
		Parent	Parent (working)	OPC2	13	FAM			
		Parent	Parent (young parent)	OPC3	14				
		Parent	Parent (single income)	OPC4	15				
		Parent	Parent (young parent)	OPC5	16				
		Carer	Carer (domestic)	OPC6	17				
		Parent	Mother (grandparent)	OPC7	18				
				INTP1					
		Parent	Parent (family)	2	19	INDT			
		Medical Professional	Occupational Therapist	INTP1	20	TSH			
				3		(Cheras)			

		Medical Professional	Physical therapist	INTP1 4	21		
		Medical Professional	Nurse	INTP1 5	22		
		Social Worker	Social Worker	OPC8	23		
		Medical Professional	Nurse (teach cooking)	OPC9	24		
		Medical Professional	Nurse (teach Sewing)	OPC1 0	25		
		Medical Professional	Physical therapist	OPC1 1	26		
		Medical Professional	Nurse (teach Grooming)	OPC1 2	27		
		Teacher	Teacher (academic)	OPC1 3	28		
		Teacher	Teacher (art and craft)	OPC1 4	29		
Col. no.	Q. no.	Variable name	Response Pattern	Code	N o.	Code Site	Region
		Stakeholder Position	Acting Position				
1>7, 11>12, 19>29	2.1 > 2.5	matrix chart (public and private organisation)	compare method of support	CMPR E1	30	PDK, UPM, CH, PSDM, KDSF, INDT, TSH	Malaysia
1>3 6>10 11>18 20>29 same	3.1 > 3.4 3.5	diagram (programs and activities) matrix chart (public and private organisation)	compare method of support in local, national and international compare public and private method of support	CMPR E2	31	PDK, PSDM, KDSF, TSH	
			programs and activities involving art and craft		32		
same	4.1(IN T) (QA)	refer 'Sparkline'	compare questionnaire if DS can do art		33		

same	4.2	refer 'Sparkline'	statistics suitable	34	
	(INT)		activity and program		
	(QA)		for ds		
same	4.3	refer 'narrative'	narrative discussion	35	
	(INT)	refer 'Sparkline'	'labour force'		
	(QA)		statistics of importance		
			of 'labour force'		
same	5.1	same	same	36	
	(INT)				
	(QA)				
same	6.1	same	same	37	
	(INT)				
	(QA)				
1 > 29	7.1	refer 'narrative'	discussion	38	PDK,
	(INT)	refer 'Sparkline'			UPM,
	(QA)		narrative 'labour force'		CH,
			devalued, abuse		PSDM,
			volunteer support,		KDSF,
			multiple task, funding		FAM,
			support, selection of the		INDT,
			best (elitism), busy life,		TSH
			managing stress, lack of		
			knowledge		
			narrative 'parent		
			support'		
			motivation support,		
			care support, neglect		
			child, misuse care		
			facility, educate		
			parents, donation		
			support, value system,		
			trust, time		

Col. no.	Q. no.	Variable name		Code	N o.	Code Site	Region
		Stakeholder Position	Response Pattern Acting Position				
1>7, 9>12, 19>22		interview	INTP				
8, 13>18 , 23>29		open conversation	OPC				

11,28,29	Teachers	total 3 people
2,8,17	Carers	total 4 people
6,7,13>16	Parents	total 9 people
18,19		
1,12,23	Social workers	total 3 people
3,5	Service Providers	total 2 people
9	Volunteers	total 1 people
4,20>22	Medical Professionals	total 8 people
24>27		

Col. no.	Q. no.	Variable name	Response Pattern	Code	N o.	Code	Regio	
		Stakeholder Position	Acting Position			Site	n	
30 > 38	1.1		Secondary Data					
		Volunteer	Volunteer (Art Professional)	INTP1 5	30	Indepen dent	Austra lia	David [intvw]
		Parent	Parent and Social worker (Volunteer)	INTP1 6	31	DSAWA		Julie[intvw]
		Teacher	Teacher	INTP1 7	32	Corpus Christi (Private)		Patrick [intvw]
		Teacher	Teacher	INTP1 8	33	Leeming (Public)		Penny [intvw]
		Parent	Parent and Social worker	INTP1 9	34	DSA Abany		Andrea (Albany) [intvw]
		Social worker	Research Coordinator	INTP2 0	35	DADAA		Natalie [intvw]
		Social worker	Research Coordinator	INTP2 1	36	DADAA		Andrea (Dadaa) [intvw]
		Social worker	Social Worker	INTP2 2	37	Workabi lity		Cynda [intvw]
		Social worker	Social Worker	INTP2 3	38	Workabi lity		Maria [intvw]
		survey	50 people	QA2	38			

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## Memorandum

To	Dr Terence Love, School of Design and Art
From	A/Professor Stephan Millett, Chair, Human Research Ethics Committee
Subject	Protocol Approval <b>HR 101/2010</b>
Date	28 September 2010
Copy	Nurul Hanim Md. Romoinoor, School of Design and Art Graduate Studies Officer, Faculty of Humanities

Office of Research and Development

Human Research Ethics Committee

TELEPHONE 9266 2784

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EMAIL [hrec@curtin.edu.au](mailto:hrec@curtin.edu.au)

Thank you for providing the additional information for the project titled "*Increasing life and employment inclusion for adults with Down Syndrome: Art-based employment and skills development*". The information you have provided has satisfactorily addressed the queries raised by the Committee. Your application is now **approved**.

- You have ethics clearance to undertake the research as stated in your proposal.
- The approval number for your project is **HR 101/2010**. Please quote this number in any future correspondence.
- Approval of this project is for a period of twelve months **28-09-2010 to 27-09-2011**. To renew this approval a completed Form B (attached) must be submitted before the expiry date **27-09-2011**.
- If you are a Higher Degree by Research student, data collection must not begin before your Application for Candidacy is approved by your Faculty Graduate Studies Committee.
- The following standard statement **must be** included in the information sheet to participants:

*This study has been approved by the Curtin University Human Research Ethics Committee (Approval Number HR 101/2010). The Committee is comprised of members of the public, academics, lawyers, doctors and pastoral carers. Its main role is to protect participants. If needed, verification of approval can be obtained either by writing to the Curtin University Human Research Ethics Committee, c/- Office of Research and Development, Curtin University of Technology, GPO Box U1987, Perth, 6845 or by telephoning 9266 2784 or by emailing [hrec@curtin.edu.au](mailto:hrec@curtin.edu.au).*

Applicants should note the following:

It is the policy of the HREC to conduct random audits on a percentage of approved projects. These audits may be conducted at any time after the project starts. In cases where the HREC considers that there may be a risk of adverse events, or where participants may be especially vulnerable, the HREC may request the chief investigator to provide an outcomes report, including information on follow-up of participants.

The attached **FORM B** should be completed and returned to the Secretary, HREC, C/- Office of Research & Development:

When the project has finished, or

- If at any time during the twelve months changes/amendments occur, or
- If a serious or unexpected adverse event occurs, or
- 14 days prior to the expiry date if renewal is required.
- An application for renewal may be made with a Form B three years running, after which a new application form (Form A), providing comprehensive details, must be submitted.

Regards,

A/Professor Stephan Millett  
Chair Human Research Ethics Committee





**JABATAN KEBAJIKAN MASYARAKAT MALAYSIA**  
**(DEPARTMENT OF SOCIAL WELFARE MALAYSIA)**

Tingkat 19-24, Menara Tun Ismail Mohamed Ali, Jalan Raja Laut, 50562 Kuala Lumpur, Malaysia  
+603-2616 5600 +603-2693 4270 / +603-2694 9395



www.jkm.gov.my



Rujukan Tuan :

Rujukan Kami JKMM: 100/12/5/2 Jld 48(1)

Tarikh 21 September 2011

Ms Nurul Hanim Md. Romainoor  
Cenderawasih Batu 11, Kg. Sg. Serai  
**43100 HULU LANGAT**  
**SELANGOR**

Dear Madam,

**INCREASING LIFE AND EMPLOYMENT INCLUSION FOR ADULTS WITH DOWN SYNDROME ART-BASED EMPLOYMENT AND SKILLS DEVELOPMENT**

We refer to the above and are pleased to inform that your application to conduct a study on the above mentioned subject has been approved.

2 Please be informed that the Department is agreeable to your request as follows:

- a) Interactive work on the organizations and agencies that liaise with the Department of Social Welfare in providing emergency and temporary shelters ( safe houses ) and other social services to Down Syndrome victims in Malaysia with the Director , Disable Persons Divisions, Department of Social Welfare , Malaysia, Kuala Lumpur.

3. Please also be guided that your study is subject to the submission of the **Agreement To Conduct A Study / Research** to the Department within **14 days** from the date of this letter. The study can only be carried out upon receiving **Letter of Approval To Conduct A Study / Research** from the Department.

4. Attached herewith is the **Agreement To Conduct A Study / Research** for your further action.

Thank you.

Yours Faithfully,

( **SHARUDIN SHAR KASHIM** )

for Director General, Department of Social Welfare Malaysia



cc

1. Director General, Department of Social Welfare
2. Deputy Director General ( Planning )
3. Deputy Director General ( Operations )
4. Director, Disable Persons Department
5. Director  
Selangor Department of Social Welfare  
Tingkat 2, Bangunan Darul Ehsan  
No. 3, Jalan Indah, Seksyen 14  
**40000 SHAH ALAM**  
SELANGOR
6. Superintenden  
Taman Sinar Harapan Kuala Kubu Bharu  
Jalan Sinaran  
**44000 KUALA KUBU Bharu**  
SELANGOR
7. Superintenden  
Taman Sinar Harapan Cheras  
KM 18, Jalan Cheras  
**43000 KAJANG**  
SELANGOR
8. Director General  
Economic Planning Unit  
Jabatan Perdana Menteri  
Blok B5 & B6  
Pusat Pentadbiran Kerajaan Persekutuan  
**62502 PUTRAJAYA**  
MALAYSIA  
( Att: Ms. Munirah Abd. Manan )
9. Ms. Zalila Abdul Rahman  
Graduate Studies Officer  
Humanities Research and Graduate Studies Office  
Curtin University of Technology  
**GPO Box U1987 PERTH**  
**WESTERN AUSTRALIA 6845**

jr/kajian/190911





Ruj. Tuan:

Your Ref.:

UPE: 40/200/19/2829

Ruj. Kami:

Our Ref.:

Tarikh:

14 July 2011

Date:

NURUL HANIM MD. ROMAINOOR  
Cenderawasih Bt. 11 Kg. Sg. Serai,  
43100 Hulu Langat  
**Selangor D.E.**  
Email: [han1mz@gmail.com](mailto:han1mz@gmail.com)

## APPLICATION TO CONDUCT RESEARCH IN MALAYSIA

With reference to your application, I am pleased to inform you that your application to conduct research in Malaysia has been *approved* by the **Research Promotion and Co-Ordination Committee, Economic Planning Unit, Prime Minister's Department**. The details of the approval are as follows:

Researcher's name : **NURUL HANIM MD. ROMAINOOR**

Passport No. / I. C No: **810605146374**

Nationality : **MALAYSIAN**

Title of Research : **"INCREASING LIFE AND EMPLOYMENT INCLUSION FOR ADULTS WITH DOWN SYNSROME: ART-BASED EMPLOYMENT AND SKILLS DEVELOPMENT"**

Period of Research Approved: **3 YEARS**

2. Please collect your Research Pass in person from the Economic Planning Unit, Prime Minister's Department, Parcel B, Level 4 Block B5, Federal Government Administrative Centre, 62502 Putrajaya and bring along two (2) passport size photographs. You are also required to comply with the rules and regulations stipulated from time to time by the agencies with which you have dealings in the conduct of your research.

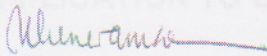


3. I would like to draw your attention to the undertaking signed by you that you will submit without cost to the Economic Planning Unit the following documents:

- a) A brief summary of your research findings on completion of your research and before you leave Malaysia; and
- b) Three (3) copies of your final dissertation/publication.

4. Lastly, please submit a copy of your preliminary and final report directly to the State Government where you carried out your research. Thank you.

Yours sincerely,



(MUNIRAH ABD. MANAN)

For Director General,  
Economic Planning Unit.

E-mail: [munirah@epu.gov.my](mailto:munirah@epu.gov.my)

Tel: 88882809

Fax: 88883961

ATTENTION

This letter is only to inform you the status of your application and **cannot be used as a research pass.**

Period of Research Approved: 3 YEARS

2. Please collect your Research Pass in person from the Economic Planning Unit, Prime Minister's Department, Parcel B, Level 4 Block 65, Federal Government Administrative Centre, 62502 Putrajaya and bring along two (2) passport size photographs. You are also required to comply with the rules and regulations stipulated from time to time by the agencies with which you have dealings in the conduct of your research.